

Title page

Full title:

Deinstitutionalisation and community living: progress, problems and priorities

Running title:

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Published as Mansell, J. (2006) Deinstitutionalisation and community living: progress, problems and priorities. *Journal of Intellectual and Developmental Disability*, 31(2), 65-76.

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Deinstitutionalisation and community living: progress, problems and priorities

Abstract

Background

Deinstitutionalisation of services for people with intellectual disabilities has become a focus of disability policy in many countries. Research for the most part supports this strategy. However, outcomes are not uniformly better for everyone who moves to community living. This paper explores reasons for variability in service quality and highlights important lessons for countries starting to modernise services.

Methods

The effects of deinstitutionalisation are summarised and emerging problems identified. The changing context of different welfare-state models and paradigms in disability and public administration are outlined.

Results

The main changes which have impacted on the implementation of deinstitutionalisation include the rise of market-based approaches, arrangements for rationing services, 'de-differentiation' and the rise of a rights-based model in disability policy.

Conclusions

The paper sets out priorities for the future development of community services. Success is likely to require a renewed focus on demonstrating improvement in the quality of life of people with intellectual disabilities and a change in staff role to provide more facilitative, enabling support of individuals, especially those with the most severe or complex disabilities.

Introduction

Although the development of community-based services as alternatives to institutional care for people with intellectual disabilities originates in the 1950s (Bruininks, Kudla, Hauber, Hill, & Wieck, 1981; Tizard, 1960), it was not until the late 1960s and early 1970s that the policy goal of deinstitutionalisation – the complete replacement of institutions by services in the community - was first articulated (Campaign for the Mentally Handicapped, 1972; Kugel & Wolfensberger, 1969). In North America, Scandinavia, Britain and Australasia this has been probably the most important change in policy and the pattern of service provision in intellectual disability in the last 50 years (Mansell & Ericsson, 1996b).

The purpose of this paper is to review progress in deinstitutionalisation and community living, in the context of different welfare-state models and changing paradigms in disability and public administration. The first part of the paper draws together evidence about the extent of deinstitutionalisation and summarises the overall effects of the replacement of institutional care with community-based services on the people served. The second part of the paper identifies emerging problems of performance of community-based services. The third part attempts to explain the emergence of these problems as a consequence of the pattern and style of welfare state modernisation. Finally the paper concludes by setting out some priorities for the future given the changes occurring now. Much of the analysis is based on British experience, but the problems identified and their causes may also be relevant in other contexts.

Progress and results of deinstitutionalisation

In North America, Europe and Australasia, the replacement of large residential institutions by a network of community-based services is well under way. The leaders in this field are probably Sweden and Norway, where all institutional provision has apparently been replaced and where the law now enshrines the right to community services (K Ericsson, 2002; Tossebro, 2004). Figure 1, for example, shows the shift in pattern of services for people with intellectual disabilities in Sweden over the last 30 years (Grunewald, 2003). Data are presented as rates per 100,000 total population to permit international comparison.

- Figure 1 about here -

In North America, the UK and Australasia, substantial progress has been made in closing institutions but continuing effort is required to complete the process. Figure 2 shows, for example, data for the USA (D. Braddock, Hemp, Bachelder, & Fujiura, 1995; D Braddock, Hemp, & Rizzolo, 2004). It shows the same pattern as for Sweden, but at a rather lower level of provision and without the complete abolition of institutions yet being achieved.

- Figure 2 about here -

Braddock *et al* (2001) report a reduction in institutional care from 4340 to 1200 places in Ontario during the 1990s and suggest that this is characteristic of developments across Canada. Similarly, although they report a shift from institutional to community-based services in Australia, a substantial number of institutional places remain. O'Brien *et al* (2001) report a change in policy favouring deinstitutionalisation and community living in New Zealand from the late 1980s.

The task of replacing institutions includes the closure of the last remaining long-stay institutions and the replacement of some of the smaller institutional campuses that formed early responses to the policy of deinstitutionalisation. Figure 3 shows data for England (Department of Health, 2004; Mansell, 1997). In 2004, there were about 750 places left in the old long-stay institutions for people with intellectual disabilities in England (Ladyman, 2003); but there were also several thousand places in 'campus' developments and new private institutions (Department of Health, 2004).

- Figure 3 about here -

In general, the pattern of change in service models in these countries is consistent. Early attempts to replace institutions led to relatively large residential homes, such as the intermediate care programme in the USA (Rotegard, Bruininks, & Krantz, 1984), the Wessex experiment in England (Kushlick, 1976) or the residential home programme in Sweden (K. Ericsson, 1996). These gave way to group homes in which 3-8 people, including people needing high levels of support, lived together with help from staff. This is probably the dominant form of community provision currently, and

is represented by models such as that developed in Andover in England (Felce & Toogood, 1988; Mansell, Felce, Jenkins, de Kock, & Toogood, 1987a), Cardiff in Wales (Lowe & de Paiva, 1991), Oregon (Horner et al., 1996), Sweden and Norway (K. Ericsson, 1996; Tossebro, Gustavsson, & Dyrendahl, 1996). More recently, dissatisfaction with group homes led to the development of what is generally called 'supported living', in which people live with individuals they choose, in housing they own or rent, receiving staff support from agencies which do not control the accommodation (Allard, 1996; Kinsella, 1993; Stevens, 2004).

In some other European countries, such as Belgium, the Netherlands, Germany, Spain and Greece, community-based services are beginning to be developed as alternatives to institutional care, although existing service structures are still dominated by institutional models (European Intellectual Disability Research Network, 2003). In the countries of the former Soviet bloc this process has only just started and there is still a large legacy of very poor quality institutional care to address. This legacy includes both levels of material and social deprivation comparable with institutions in Britain, Scandinavia and the USA in the past (Mansell, Beadle-Brown, & Clegg, 2004) and also inhumane methods of care and treatment. For example, attention has been drawn to the use of cage beds in institutions in the Czech Republic, Hungary, Slovakia and Slovenia (Mental Disability Advocacy Center, 2003). In some Romanian and Bulgarian institutions, mortality rates exceed one in five residents (Lewis, 2002). There continues, therefore, to be an urgent need to replace institutional care in these countries.

The evaluation of community-based models of care for people with intellectual disabilities, compared with the institutions they replace, generally shows a relatively clear picture. Over and over again, studies have shown that community-based services are superior to institutions. Recent reviews illustrate typical findings. Kim, Larson and Lakin (2001) reviewed 29 comparative and longitudinal American studies between 1980 and 1999. In terms of adaptive behaviour, 19 studies showed significant improvements and two studies showed significant decline. In terms of challenging behaviour, five studies found significant improvements while two studies found a significant worsening in behaviour. Of the remaining studies where change was not

significant, 8 reported a trend towards improvement while six reported a trend towards decline.

Young *et al* (1998), reviewing Australian studies of deinstitutionalisation shows the pattern in relation to a wider range of outcomes (Figure 4). In six of the nine areas, the majority of studies report positive effects and in the remaining three the majority report no change.

- Figure 4 about here -

This general finding, that community-based service models achieve better results for the people they serve than institutions, has rightly sustained government policies of deinstitutionalisation and community living.

Problems of deinstitutionalisation

However, right from the outset, evaluation has shown that this general picture of improved outcome is complicated by variation.

Different kinds of services of the same general type achieve widely differing results when compared on the same measures. Comparing different models of service, the ranges of scores achieved overlap considerably. Figure 5, for example, shows the mean and range of scores for resident engagement in meaningful activity reported in Emerson and Hatton's (1994) review of 46 British studies of 2350 people. It shows that, on average, staffed housing achieves better results than small institutions which in turn achieve better results than large institutions. But the considerable overlap in the ranges of scores indicates that better large institutions can produce outcomes as good as weaker smaller settings; and that better small institutions can achieve outcomes as good as weaker staffed housing.

- Figure 5 about here -

The existence of this variation tends to undermine the consensus supporting deinstitutionalisation and community living. It removes one of the most powerful incentives that decision-makers could experience – the unequivocal evidence of their

own eyes, that community services are better for everyone, all of the time. It casts doubt on the value of the financial investment community services require, by suggesting that some congregate care facilities can achieve results as good, even though they provide fewer staff and therefore cost less.

Variation in performance reflects, in part, the range of abilities and characteristics of residents. People with higher support needs – whether because of the nature of their intellectual and physical disabilities, their challenging behaviour or social impairment, often experience less good outcomes than people who are more independent (Felce & Emerson, 2001). Figure 6 shows, for example, the average engagement in meaningful activity at mealtimes by people with high, medium and low support needs. These data are drawn from a recent study of group homes in England (Mansell, Beadle-Brown, Macdonald, & Ashman, 2003b). People with the highest support needs experience less good outcomes. In the general context of deinstitutionalisation, they are also typically the last to get out of institutions (Wing, 1989) and, if they experience difficulties in living in the community, most at risk of being returned (Intagliata & Willer, 1982).

- Figure 6 about here -

However, variation does not only reflect resident characteristics. Demonstration projects have shown that it is possible to greatly increase the level of outcomes achieved for people with the most severe disabilities. Figure 7, for example, is taken from Mansell (1995) and compares observations taken in different settings in a longitudinal study of people with severe and profound intellectual disabilities and very serious challenging behaviour. People in this study moved from institutional wards or ‘special units’ to individually tailored placements in small staffed houses. It shows a doubling of average engagement in meaningful activity by residents and of assistance and other contact provided by staff.

- Figure 7 about here -

Variation in the performance of community-based services also reflects characteristics of the design of the services themselves. Most importantly, it reflects differences in

staff performance. In a series of studies by Felce and his colleagues in Wales, by Emerson and Hatton and by the author and colleagues at the Tizard Centre, the way staff provide support to the people they serve has been singled out as a key determinant of outcome. This result has been found in comparative studies of houses versus other settings (Felce, 1996, 1998; Felce, de Kock, & Repp, 1986; Felce, Repp, Thomas, Ager, & Blunden, 1991; Mansell, 1994, 1995; Mansell, Jenkins, Felce, & de Kock, 1984), in experimental studies within houses (Bradshaw et al., 2004; Jones, Felce, Lowe, Bowley, Pagler, Gallagher et al., 2001; Jones et al., 1999; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002) and in regression studies (Felce, Lowe, Beecham, & Hallam, 2000; Hatton, Emerson, Robertson, Henderson, & Cooper, 1996; Mansell, Beadle-Brown, Macdonald, & Ashman, 2003b). In general, it appears that, once the material and social deprivation found in institutions is addressed, by their replacement by small-scale services in the community, the main predictors of at least some important outcomes are resident need for support (ie their adaptive behaviour) and the care practices of staff (particularly the extent to which they provide facilitative assistance or 'active support' (Brown, Toogood, & Brown, 1987; Felce, Jones, & Lowe, 2000; Jones et al., 1996; Mansell, Beadle-Brown, Ashman, & Ockendon, 2005; Mansell, Felce, Jenkins, de Kock, & Toogood, 1987b)).

Why are community-based services so variable in their performance? Why is it the case that the initial promise of community services – the dramatic results achieved by the pioneer projects of 25 years ago – is not being realised on a wider scale? Broadly, two interpretations for this failure have been offered (Mansell & Ericsson, 1996a). Some authors have argued that the ideology of institutions persists in group homes and can only be overcome by a further move to supported living (eg K. Ericsson, 1996; Stevens, 2004). Others have argued that variable results can be seen as a problem of weak implementation (eg E. Emerson & Hatton, 1994; Mansell, 1996; McGill & Mansell, 1995).

Generally there is very little research comparing supported living with group homes. Howe, Horner and Newton, (1998) compared 20 people in supported living with 20 matched individuals in group homes and found that people in supported living did a wider range of community activities, more frequently and did more preferred activities than people in group homes. They also did activities with more people and did more

activities with each of those people. Emerson *et al* (2001) directly compared supported living, small group homes and large group homes and found few differences between supported living and small group homes. Those in supported living had more choice on average about where they lived, with whom they lived and day-to-day issues than those in group homes. They were more likely to have had their home vandalised and were perceived to be more at risk of exploitation by people in the local community. They were less likely than those in group homes to have scheduled activities but had more recreational or community-based activities. There were no differences between supported living and small group homes in family contact, size of social network, health, accidents, abuse or risks other than exploitation by people in the local community. A second study in this group (E Emerson *et al.*, 1999) compared dispersed housing (group homes and supported living) with institutions and found no difference in the proportion of time residents were engaged in non-social activity (the average for both groups being 11%).

This is at best a mixed picture and suggests that problems of implementation are important even in new service models. Attending to implementation implies a renewed focus on training and the motivation of staff. Jones *et al* (2001) showed that failure by service managers to include the hands-on component of active support training for their staff was associated with failure to change staff performance and failure to improve user engagement in meaningful activity. In an unpublished study, the author and colleagues have recently found that training of the whole staff team in active support predicts implementation and outcome. Frequency of supervision and teamwork were also predictive, suggesting that the role of the first-line manager – the team-leader – in directing and shaping the quality of support offered by staff is pivotal.

Yet training in active support or other kinds of direct help which enable people – especially people with the most severe disabilities – to grow and develop as individuals and to engage in meaningful activity and relationships in their community is rare. In the UK, most training undertaken by support workers either covers minimum statutory requirements, such as health and safety, or concerns an introduction to intellectual disability at the most basic level (Carnaby, 2003; Ward, 1999).

The motivational framework within which staff work also does not seem to prioritise enabling service users to engage in meaningful activity and relationships. Mansell and Elliott (2001) found that when support workers were asked which activities would produce consequences for them if they did them or failed to do them, the task for which most support workers reported consequences was administration, rather than enabling resident activity.

Changing context of deinstitutionalisation

This, of course, raises the question why training and leadership are not being given the priority they require. The third part of this paper explores some of the major changes taking place in western welfare systems and their impact on the development of services. In particular, attention is focused on three changes: the growth of market-based approaches to service provision, the de-differentiation of intellectual disability services and the rise of a rights-based approach to disability.

Following Esping-Andersen (1990), it is useful to distinguish three ideal types of capitalist welfare state: the social-democratic, liberal and conservative.

In the social-democratic model, characterised by countries like Sweden or Norway, universal public services are provided as of right. The model shows a high degree of de-commodification, in that pricing and payment for services is done by the state on a collective basis. In this system, waiting-lists are not used to ration services; once eligibility is demonstrated, services are provided.

In the liberal model – the dominant model in the so-called ‘Anglo-Saxon’ countries – the dominant idea is that the private life and freedom of the individual should remain untouched and that public intervention should occur only in cases where individual solutions to problems do not work. Welfare is predominantly organised on a means-tested basis so that most services are restricted to the poorest. Rights are less well developed than in social-democratic welfare states and this, coupled with individual means-testing, often leads to the stigmatization of welfare recipients so that the welfare system is socially stratified.

The conservative model is founded on 'normal' employment relationships and families and is typified by Germany or France. The claim to welfare is based on the contributions made and thus social rights are closely linked to class and status. These systems tend to be characterised by large corporate arrangements for funding and providing services. They sit between the social-democratic and liberal models in the degree to which welfare is treated as a commodity.

These are, of course, ideal types, and there are examples of each approach co-existing in most countries. However, the point of this distinction is the growth of the liberal, market-based model, in all western societies. In the face of dramatically increasing welfare expenditure, all these countries have made greater and greater use of markets to structure welfare provision. Governments hope, by these means, to secure greater efficiency. So for example, in Sweden in recent years people with disabilities are being given the choice to move to supported accommodation provided by not-for-profit organisations away from their municipality. In continental Europe, several conservative countries are developing personal budgets for people with disabilities as a way of beginning to break up the corporate structures that control service provision in pursuit of a 'mixed economy of welfare' (Wistow, Knapp, Hardy, & Allen, 1992).

The characteristics of the service arrangements introduced through these reforms include:

- ◆ Definition of taxpayers as prime customers with public servants – not service users
- as proxy decision-makers
- ◆ Eligibility criteria to ration availability of services, with the replacement of rights-based eligibility by discretionary managed budgets
- ◆ Focus on value-for-money emphasising basic, general, minimum standards as 'good enough', not the full range of outcomes for everyone (including those with the highest support needs)
- ◆ Reduced emphasis on planning, on service models and on locality in favour of 'choice'.

The effects of these reforms are evident. Service rationing halts or even reverses the sharing of costs of disability more evenly between families and the wider community¹. Entitlement to services as a right is replaced by access only in extreme crisis. The lack of planning means that services are under-developed, so that there is a lack of flexible options and of capacity in the system. Lack of capacity extends to under-investment in staff and staff training, so that care work is low-paid and staff turnover is high. Priority is given to outcomes like placement availability rather than placement quality.

In services for people with intellectual disabilities, these changes are seen most starkly in the way challenging behaviour is managed. Effective responses to challenging behaviour require organisation and management of services as a system of interdependent components, in which there are many different options (Mansell, McGill, & Emerson, 1994). To give two examples: good respite care for people in crisis requires the funding flexibility to offer different options for different people in different situations, rather than one 'unit' which brings everyone in crisis together; efficient management of challenging behaviour requires that many services in a locality can provide the skilled lifestyle support indicated by the term 'positive behaviour support', so that services adopt a preventative approach minimising challenging behaviour and managing it effectively where it occurs.

This is not happening. Instead, typical arrangements involve the purchasing of large numbers of residential services which are not able to cope with challenging behaviour. The dominant model of care in these services is unskilled minding. In consequence, when crises occur – either at home or in supported accommodation – there are insufficient local services that can respond well. The response to this is the growth of out-of-area placements, ostensibly for assessment and treatment but often providing long-term care.

In Britain, there has been the development of specialised challenging behaviour homes which group people together, in spite of evidence that this produces worse results for

¹ When governments complain that expenditure on disability is rising then arguably it is not rising at all. Apart from the effect of general population growth, apparent increases may be due to two other factors. First, the reclassification of unemployed people as disabled in order to reduce politically sensitive unemployment figures (Department of Work and Pensions, 2004). Second, the transfer of more of the cost of disability, hitherto borne by the family and the person with disabilities themselves, to the community. These costs, when borne by people with disabilities and their families, include lost years of life, lost opportunities and lost quality of life as well as the direct costs of disability.

people (Mansell & Beadle-Brown, 2004; Mansell, Beadle-Brown, Macdonald, & Ashman, 2003a; Robertson et al., 2004). Larger, more institutional services are also being developed, including explicit proposals to reinvent large hospital campuses (Care Principles, 2004; St Luke's Hospital Group, 2004). Many of these more institutional services are remote from where people live, weakening family and friendship ties and creating isolated ghettos of people with challenging behaviour in semi-rural settings. For example, Beadle-Brown *et al* (2005) estimate that in the English county of Kent, with a population of 1.6 million people, between 30 and 50% of all residential places are occupied by people placed in residential care from other areas.

The second relevant factor is what Sandvin (1996) refers to as *de-differentiation*. De-differentiation is the loss of special, separate policies and service structures for people with intellectual disabilities and their replacement by general policies and structures. De-differentiation is the consequence both of the belief in intellectual disability – for example in the normalisation literature - that specialist services are bound to be discriminatory, and of the spread of deinstitutionalisation to other client groups so that implementation issues are addressed as part of the general modernisation of social care.

De-differentiation involves the replacement of specialist models tailored to the needs of people with intellectual disabilities with generic models which have to apply to other client groups. So, for example, the invention of regulatory systems, occupational health and safety arrangements and other mechanisms that apply to all care services inevitably impose constraints based on assumptions that may not be relevant in intellectual disability. The consequences of de-differentiation may include greater competition for priority for resources and a lack of recognition of special issues. In a sense, reform and improvement opportunities in intellectual disability services are increasingly in competition with those for other client groups, at a time when understanding of the specific issues and problems of intellectual disability may be less among public agencies which have a generic rather than specialist focus.

The third contextual factor is the rise of a rights-based model of disability and particularly of what is called the 'social model'. Of course a strong rights-based

approach to disability offers the prospect of removing some of the negative features of the market – the waiting lists, the out-of-area placements, the minimum standards approach. But the rise of the social model has also served to de-emphasise the impairments people with disabilities have. The impression is given – for example in the much-lauded English White Paper *Valuing People* (Department of Health, 2001) – that people with intellectual disabilities know what they want and just need services to give it to them. For some people this, though an oversimplification, is likely to be true. But for many people with intellectual disabilities the nature of their cognitive impairments means that other people will need to help them make decisions or make decisions on their behalf (PMLD Network, 2001; Ware, 2004); and their quality of life will depend crucially on the mediating effect of skilled support from others (Mansell & Elliott, 2001).

Yet in the twenty-five years through which the deinstitutionalisation process has taken place, the idea of developmental intervention to help people overcome their intellectual disability has almost completely disappeared as a priority. Long-term follow up of people moving from institutions in England shows that, after the initial rapid increase in independence on moving out of institutions, five and twelve years on there is no growth in adaptive behaviour (P Cambridge et al., 2001; P. Cambridge, Hayes, Knapp, Gould, & Fenyo, 1994). One reason for the poorer performance of ‘second-generation’ community-based services may be that developmental intervention is no longer considered as important as it was.

Implications of changed context

These three changes, taken together, provide the context within which the performance of community services is likely to be judged in future.

The rise of market-based approaches to resource allocation and decision-making has placed new service models in competition with each other. There is less commitment to particular philosophies and models *a priori*, with an increased willingness to judge services on the basis of ‘payment by results’. A central issue for the future is just which results decision-makers give priority to. Despite the emphasis in policy documents on rights and the quality of life of people with intellectual disabilities, there is plenty of

anecdotal evidence from service providers that the market currently operates to maximise number of places rather than quality.

De-differentiation has added competition for attention and resources from other groups. Not only are service models in competition with each other, now different client groups compete. It has also created obstacles and hurdles through 'one-size-fits-all' policies. De-differentiation has also made it harder to identify the special situation of people with intellectual disabilities. A critical question for proponents of better-quality services for people with intellectual disabilities will be how they can achieve the benefits of social integration for individuals and for the whole group while at the same time retaining enough knowledge and recognition to ensure that special needs are noticed.

The rise of the social model of disability has de-emphasised intervention to help people gain skills and independence. Staff training emphasises anti-discriminatory practice and the promotion of choice and opportunity for people who can express clear intentions – not the skilled professional support required to enable people with significant intellectual disabilities to continue to grow and develop throughout their lives.

The implications of these broad changes in context are important. Deinstitutionalisation and community living has very largely been sustained, in the policy arena, through the promotion of a particular philosophy. Great changes have been carried through on the assumption that community-based services are better than the institutions. This is unlikely to be enough in a harsher, more sceptical policy climate. The pursuit of more staff, smaller services, tenancy status rather than group homes, in the absence of unequivocal evidence that these things make a difference, is unlikely to carry sway. If community services continue to provide very variable results, and overall if they are seen to be not much better than sanitised institutions, then they will lose out in the policy marketplace.

Furthering the improvement of services for people with intellectual disabilities based in the community, and perhaps even holding on to the gains that have already been made, is likely to depend on being able to demonstrate that the potential they offer is

achieved in practice. The pressures on decision-makers, in a market-based system, will be to focus on price and volume rather than quality, and to under-invest in planning and infrastructure. Given this, it will fall to an alliance of those representing service user interests and service providers to combine the rights-based discourse that identifies quality as well as quantity as essential, with evidence that services really can achieve it. Critical in this will be redefining the role of front-line staff as skilled enablers of user participation and development.

So this is a plea for empiricism. For judging services by their results, not by intentions. For rediscovering the educational and facilitative role of staff. For shaping up staff performance – through leadership and training – so that the potential created by community location and extra staffing is realised. The goal is that one should be able to take families, or politicians, to visit people with intellectual disabilities living in the community and they should see something so strikingly different from institutional care, so evidently skilful in the way it creates opportunities in spite of complex needs, that they are unable to resist giving it their support.

Acknowledgements

Keynote address given at the 39th meeting of the Australasian Society for the Study of Intellectual Disability, Adelaide, 10 November 2004. The author would like to thank Julie Beadle-Brown for assistance and comments on the paper.

Author note

Preparation of this paper was unfunded. The author has no conflict of interest in its preparation.

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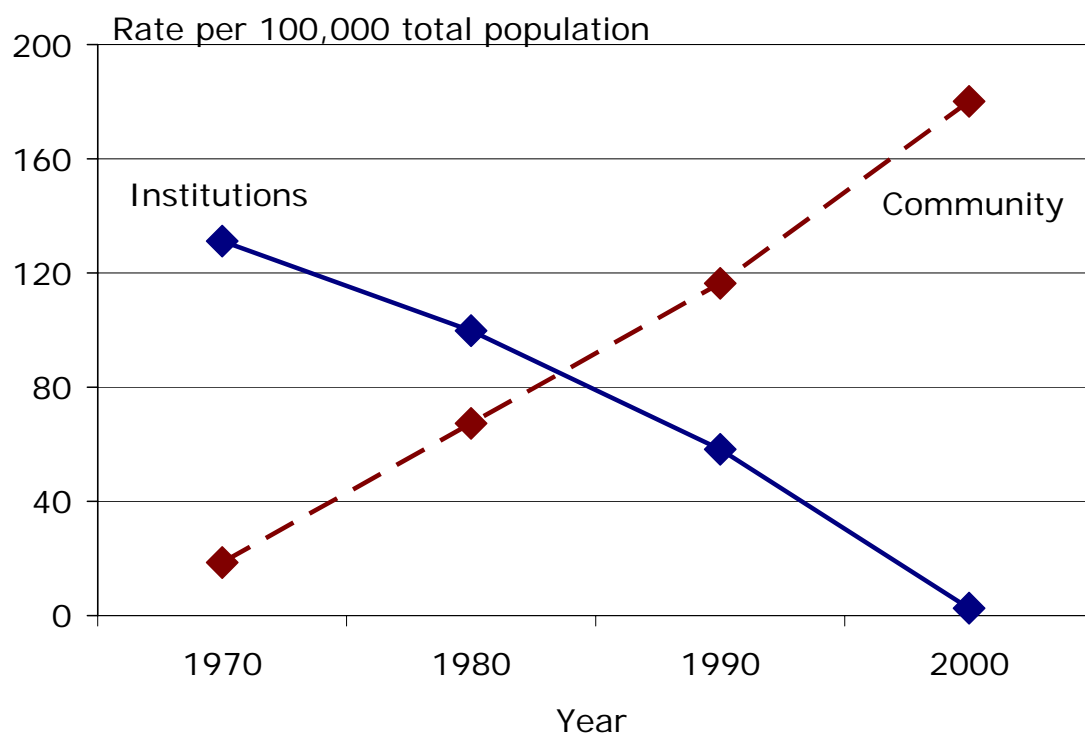
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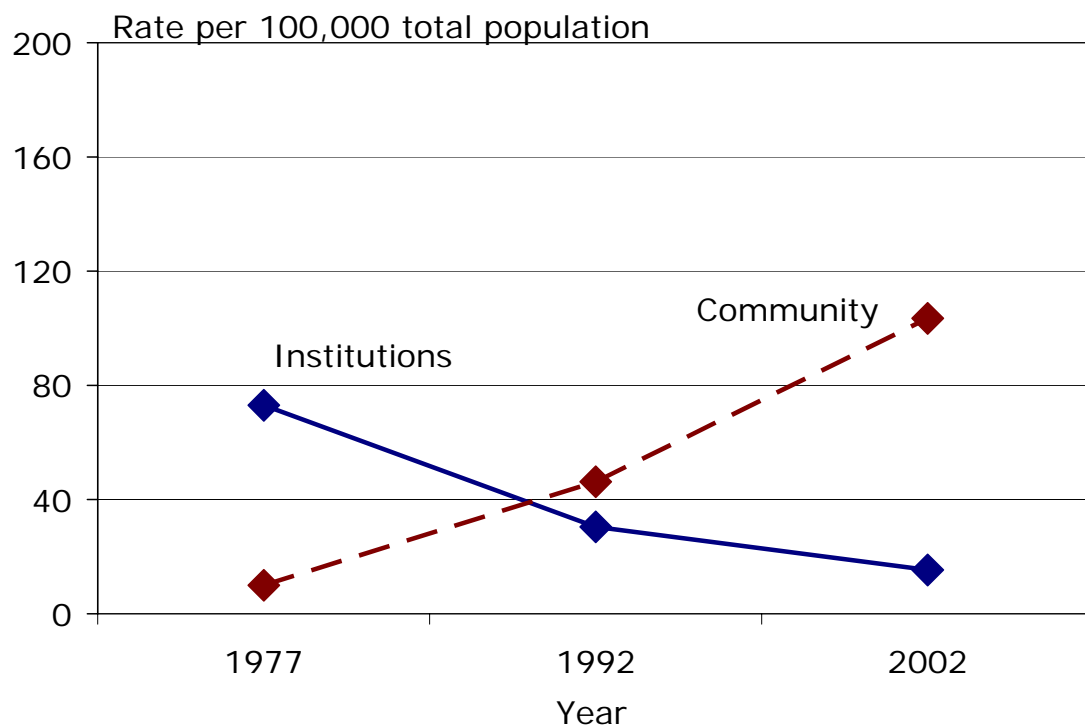
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Figure 1: Deinstitutionalisation and community living in Sweden



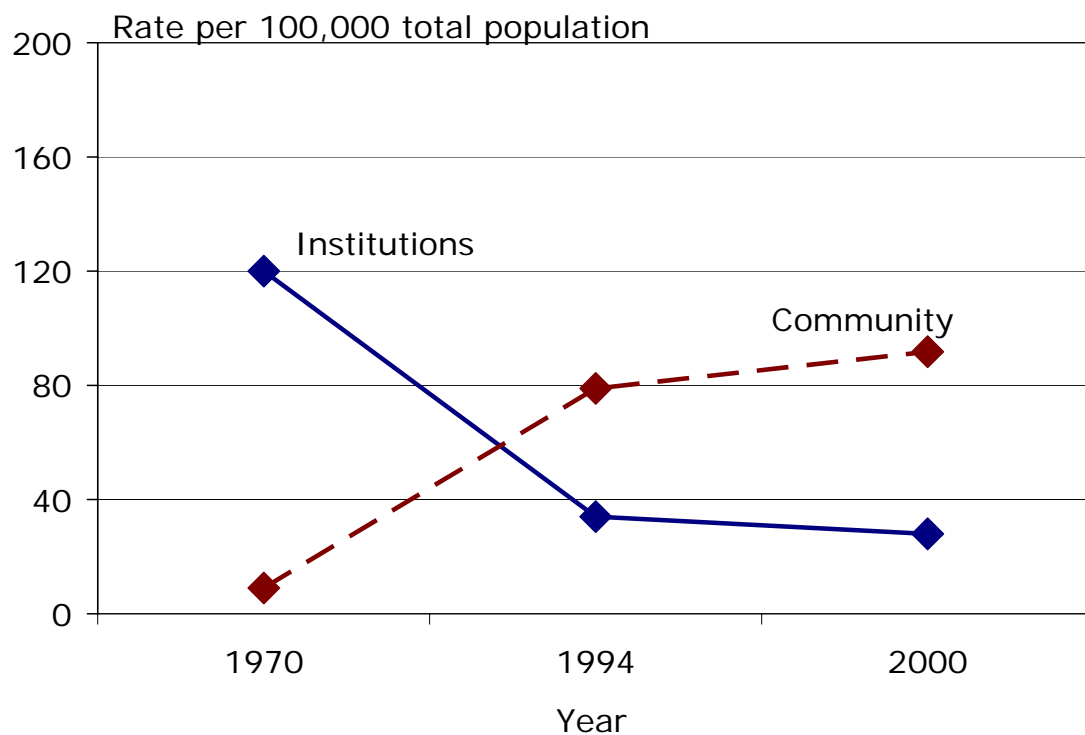
(Grunewald, 2003)

Figure 2: Deinstitutionalisation and community living in the USA



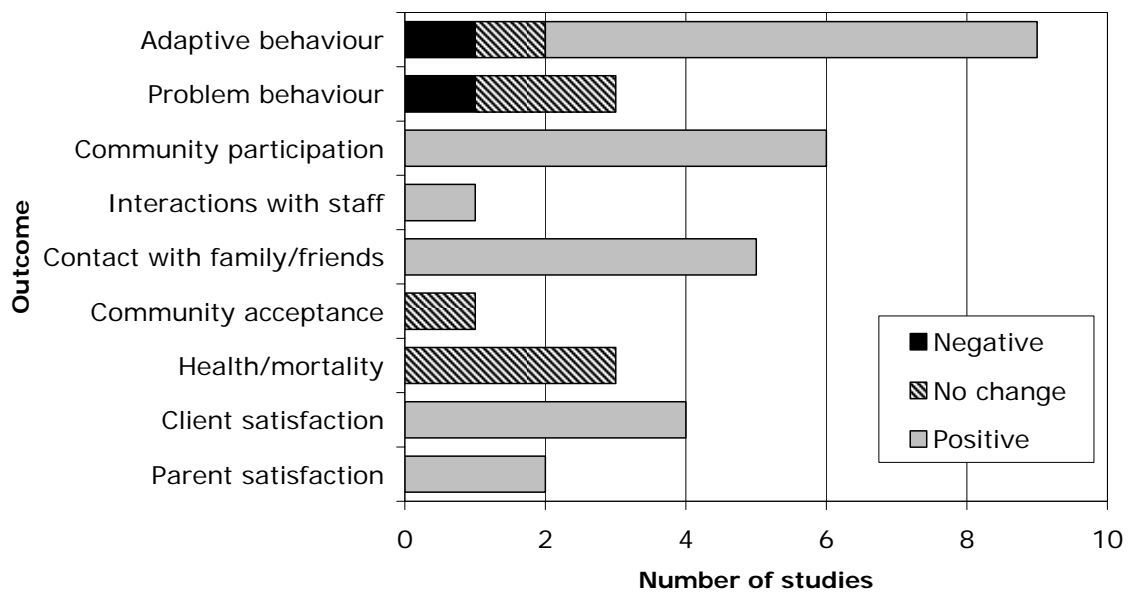
(Braddock, Hemp and Rizzolo, 2004)

Figure 3: Deinstitutionalisation and community living in England



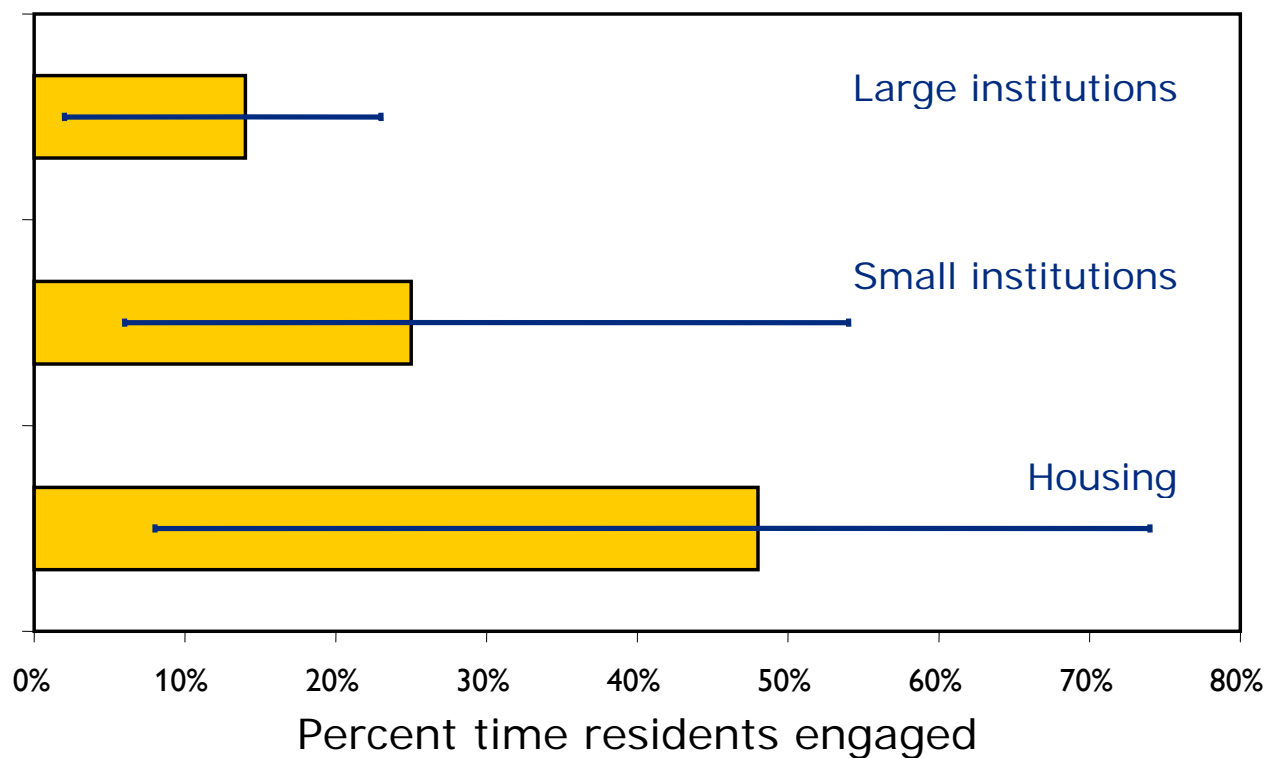
(Department of Health, 2004; Mansell, 1997)

Figure 4: Results of Australian studies of deinstitutionalisation



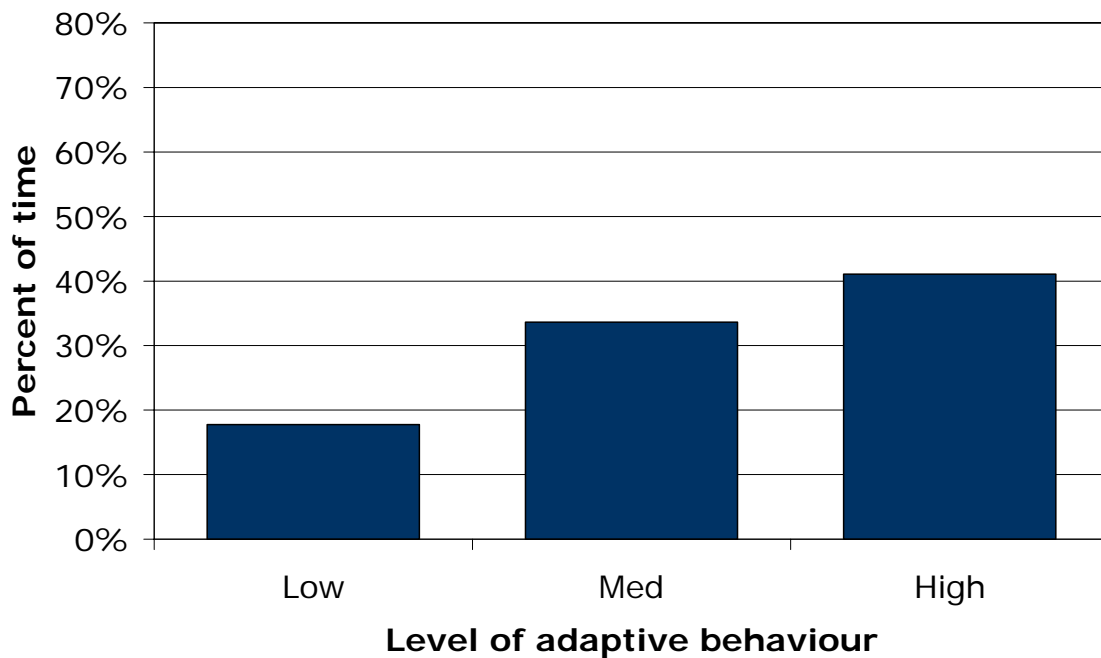
(Young *et al.*, 1998)

Figure 5: Variability in performance of residential settings in England and Wales



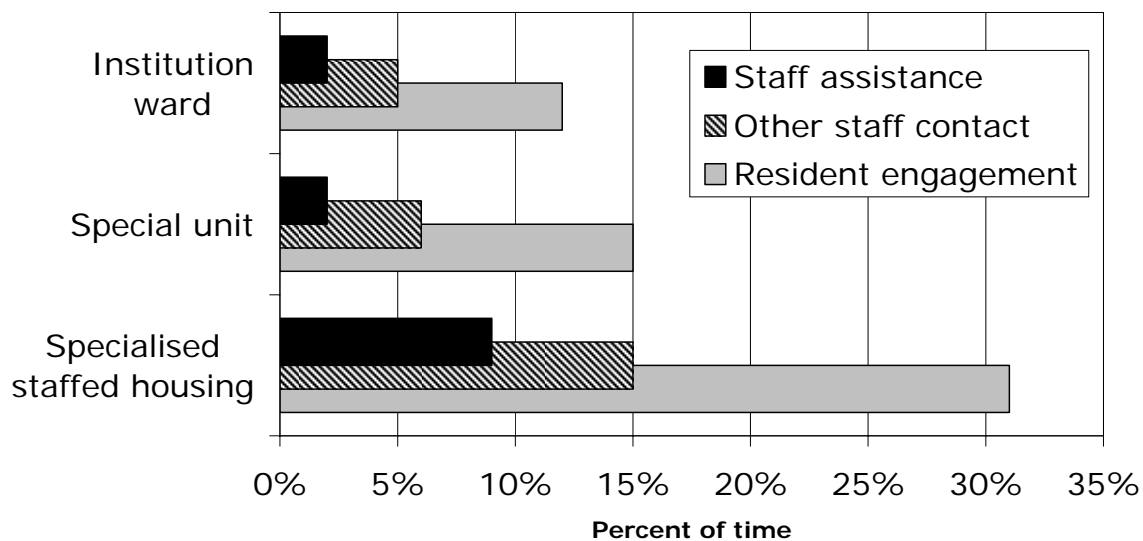
(Emerson and Hatton, 1994)

Figure 6: Engagement in meaningful activity at mealtimes by people with high, medium and low support needs



(from Mansell *et al.*, 2003)

Figure 7: Average engagement in meaningful activity in demonstration projects



(Mansell, 1995)