

Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities¹

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Introduction

The gradual abandonment of large residential institutions² and their replacement by small-scale services to enable people to live well in the community has probably been the most significant policy development in intellectual disability in the post-war period (Mansell and Ericsson, 1996). This process of ‘deinstitutionalisation’ is well advanced in Scandinavia, the United States of America, Canada, the United Kingdom, and Australasia. In these countries, the policy debate about whether to provide institutions or community services is largely resolved. The questions that remain are those of implementation and particularly of whether the kinds of supported accommodation that have been provided replicate institutional features and should themselves be reformed. For many other countries, the debate between institutional and community services has never been particularly important because most people with intellectual disabilities live with their families and services to support them are relatively undeveloped. In these countries, it should be possible to develop community-based services directly, without going through a phase of institutional care. In a third group of countries, the dominant form of service provision remains institutional care and the question of whether and how to replace this remains a matter of debate. For example, many central and eastern European countries provide institutions of very poor quality and currently have proposals to renovate, upgrade and extend them using international funds instead of replacing them with services to support people in the community.

The international legal framework sets out the right of disabled people to live in the community. The United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), which came into force in May 2008, recognises this right through Article 19, which entails the provision of “a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.” The Convention obliges states to develop community living that will replace institutional care through a process of ‘progressive realisation’. This requires states to take measures to the maximum of their available resources with a view to achieving progressively the full realisation of the rights involved. They must, therefore, move in the direction of realising the rights of disabled people but they are allowed to do so at a rate determined partly by the resources available to them.

Good information is central to this process of reform and service development. People making decisions about the pace and scope of change, the kind of services needed and the organisation and management of those services are often faced with strongly-held opinions

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² The word ‘institution’ has more than one meaning. It can mean a set of arrangements or practices, with associated values, beliefs and conventions. In this sense many social organisations can be described as ‘institutions’. However the sense used here is of the institution as a residential establishment possessing some or all of the negative characteristics associated with the idea of the ‘total institution’ (Goffman, 1968).

from proponents of different service models. The purpose of this position statement by the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disability is to set out concisely the evidence comparing institutional to community-based services and to draw out the main implications for policy-makers.

Definition of residential institution

At the beginning of the process to replace institutions with community living, typical institutions had several defining characteristics:

1. They were large establishments serving tens, hundreds or even thousands of people.
2. They were physically and socially segregated from the wider society.
3. Whether by policy or for want of alternative sources of support, residents were not easily able to leave them to live elsewhere.
4. Material conditions of life were worse than for most people in the wider society.

The nature of care provided in these institutions was typically characterised by *depersonalisation* (removal of personal possessions, signs and symbols of individuality and humanity), *rigidity of routine* (fixed timetables for waking, eating and activity irrespective of personal preferences or needs), *block treatment* (processing people in groups without privacy or individuality) and *social distance* (symbolising the different status of staff and residents) (King, Raynes and Tizard, 1971).

The relationship between institutional care practices and the size and segregation of institutions was not accidental. The care practices reflected attitudes and beliefs which it was necessary for staff to hold in order to cope with the task they faced (Goffman, 1968). These practices in turn reinforced attitudes and beliefs about the residents as different from and less valuable than other people (Wolfensberger, 1975). Even where institutions were established with humanitarian motives, they became overwhelmed by these pressures.

This account represents the 'ideal type' of residential institution. Variations in size, segregation, material conditions and care practices occur. In countries which have replaced large residential institutions with services in the community, it has been recognised that it is possible to transplant many of the features of institutions to these new services. This has led to definitions of institution such as that proposed by People First of Canada:

“An institution is any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place where people do not have, or are not allowed to exercise, control over their lives and their day-to-day decisions. An institution is not defined merely by its size.”

Definition of community living

The aim of community living arrangements is to enable people with intellectual disabilities to use the same range of accommodation, living arrangements and patterns of living that are available to the rest of the population, and to have a good quality of life, participating as full citizens in social, cultural and economic activities to the extent and in the ways the individual chooses. Thus community living involves:

1. Using accommodation located among the rest of the population, which is adequate, appropriate and accessible to the individual
2. Using the range of accommodation options ordinarily available to the wider population

3. Enabling people, to the greatest extent possible, to choose where, with whom and how they live
4. Providing whatever help is required to enable people to participate successfully in the community

The use of the term 'community' reflects the importance attached to acceptance and assistance from members of the public in their roles as neighbours, friends, shopkeepers, colleagues and so on, sustaining the disabled person through supportive relationships that are not solely based on payment. Community services are intended to support rather than replace such sources of help. However, recognising the difficulty most communities have of sustaining people with intellectual disabilities (especially those with substantial or complex disabilities), and the history of discrimination and exclusion that result from this, community living arrangements also entail the provision of services. These involve modifications to generic public services (such as transport, health care and education) to adjust them so that people with intellectual disabilities receive the same standard of service as other people; and special services such as advice, practical help and assistance with activities of daily living.

In terms of accommodation, early attempts to replace institutions led to relatively large residential homes, such as the intermediate care programme in the USA (Rotegard, Bruininks and Krantz, 1984), the Wessex experiment in England (Kushlick, 1976) or the residential home programme in Sweden (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 and Toogood, 1988; Mansell *et al.*, 1987a), Cardiff in Wales (Lowe and de Paiva, 1991), Oregon (Horner *et al.*, 1996), Sweden and Norway (Ericsson, 1996; Tossebro, Gustavsson and Dyrendahl, 1996). More recently, dissatisfaction with group homes has 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). This development has often been linked with arrangements to give control of funding to the disabled person or their representatives to purchase the services they need directly (eg as 'individual budgets' or 'direct payments'), rather than services being defined and allocated by public bodies (Glendinning *et al.*, 2008; Moseley, 2005).

Comparison of institutional care vs. community living

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.

The large number of relevant studies have been summarised in a series of reviews which 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, eight reported a trend towards improvement while six reported a trend towards decline.

Emerson and Hatton (Emerson and Hatton, 1994) reviewed 71 papers published between 1980 and 1993 which examined the effect of moving from institutional to community services in the UK and Ireland. In five of six areas (competence and personal growth, observed challenging behaviour, community participation, engagement in meaningful activity and contact from staff), the majority of studies reported positive effects; only in one area (reported challenging behaviour) did the majority of studies report no change. Young *et al* (1998), reviewing 13 Australian studies of deinstitutionalisation published between 1985 and 1995, showed a similar pattern. In six of the nine areas studied (adaptive behaviour, client satisfaction, community participation, contact with family/friends, interactions with staff and parent satisfaction), the majority of studies report positive effects and in the remaining three (problem behaviour, community acceptance and health/mortality) the majority report no change. Kozma, Mansell and Beadle-Brown (2009) reviewed 67 papers published between 1997 and 2007. In seven out of ten areas (community presence and participation, social networks and friendships, family contact, self-determination and choice, quality of life, adaptive behaviour, user and family views and satisfaction) the majority of studies showed that community living was superior to institutional care. In three areas (challenging behaviour, psychotropic medication and health, risks and mortality) research reported mixed or worse results.

Thus the general finding is that community-based service models achieve better results for the people they serve than institutions.

There is 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.

The relatively large body of research comparing institutions with community-based services also shows 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 (Mansell, 2006). 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 and Emerson, 2001). 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 and Willer, 1982).

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 (Mansell, 1995) to a level higher than achieved in any institutional setting. It also reflects characteristics of the design of the services themselves (Felce and Perry, 2007). Most importantly, it reflects differences in staff performance. Previous research has suggested that the way staff provide support to the people they serve is a key determinant of outcome. This result has been found in comparative studies of houses versus other settings (Felce, 1996, 1998; Felce, de Kock and Repp, 1986; Felce *et al.*, 1991; Mansell, 1994, 1995; Mansell *et al.*, 1984), in experimental studies within houses (Bradshaw *et al.*, 2004; Jones *et al.*, 2001; Jones *et al.*, 1999; Mansell *et al.*, 2002) and in regression studies (Felce *et al.*, 2000; Hatton *et al.*, 1996; Mansell *et al.*, 2003). 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 and Brown, 1987; Felce, Jones and Lowe, 2000; Jones *et al.*, 1996; Mansell *et al.*, 2005; Mansell *et al.*, 1987b)).

Thus the implication is that the shift from institutional care to living in the community is a necessary but not a sufficient condition for better outcomes for all residents. In addition to the change of accommodation, it is necessary to change the kind of staff support provided.

Different or new institutions

Most of the comparative research on institutions and community living comes from those countries which moved first to replace institutions which therefore have well-developed community services. These are Sweden and Norway, the United States of America and Canada, Great Britain and Australia.

Institutions continue to be the dominant form of residential provision for disabled people in many other countries. For example, a recent study estimates that over a million people live in residential institutions in Europe (Mansell *et al.*, 2007). Although some of these institutions are very similar to those closed in other countries, some are smaller, in more modern buildings, with higher staff ratios and expenditure. It is sometimes argued that these institutions are different from those included in the studies cited and that they provide a good quality of life for their residents. This position is not supported by the available empirical data. There are very few studies using quantitative measures of the range of outcomes addressed by the existing literature – Kozma, Mansell and Beadle-Brown (2009) found only nine of 67 papers in their review studied non English-speaking countries. A recent study of institutions in France, Hungary, Poland and Romania (Mansell, Beadle-Brown and Clegg, 2004) showed that although there were differences between institutions in different countries, they provided similarly poor outcomes for residents as institutions studied in the UK, USA and Sweden in the 1970s.

Similarly, an audit of residential services in England, including small institutions provided as part of early attempts of replace large institutions, concluded that they failed to offer the improved quality of life achieved by the best services (Healthcare Commission, 2007). The UK government has now decided to close these 'campus' developments as well as the remaining large institutions (Department of Health, 2007).

A variation on the argument that some large, congregate settings can achieve acceptable standards of care is provided by the proponents of ‘village’ or intentional communities (Cox and Pearson, 1995). These are a marginal form of provision, accounting for about 2% of residential provision in England. A comparative evaluation by Emerson et al (1999) showed a different balance of benefits and disbenefits between village communities and dispersed housing – each had advantages and disadvantages. However, this study was not able to control for level of disability, so that people in village community settings were much less disabled than those in dispersed housing. Therefore the differences between types of setting may reflect differences in the people served by them rather than in the services themselves. In a subsequent study of ‘cluster-housing’ in England, Emerson (2004) showed that, once resident characteristics were controlled, people supported in cluster housing were more likely to live in larger settings, be supported by fewer staff, be exposed to greater changes/inconsistencies in living arrangements (their home also being used for short-term care for others and greater use of casual staff), be exposed to more restrictive management practices (seclusion, sedation, physical restraint, polypharmacy), lead more sedentary lives, be underweight, and participate in fewer and a more restricted range of leisure, social and friendship activities.

A recent review of congregate housing compared with dispersed housing in the community (Mansell and Beadle-Brown, 2009) showed that dispersed housing was superior to cluster housing on the majority of quality indicators studied. The only exception to this is that village communities for people with less severe disabilities have some benefits. However, these only serve a less disabled population and they depend on a supply of people willing to live communally with disabled residents. They are therefore an important part of the spectrum of service provision but they are only ever likely to occupy a niche in the market for care. They are unlikely to be a feasible option across the board for people with intellectual disabilities.

Cost-effectiveness

Data on cost-effectiveness of institutional and community models has recently been reviewed by Felce and Emerson (2005) and Mansell *et al* (2007). These reviews note the importance of ensuring like-for-like comparisons, in which all costs and outcomes are included, which take account of resident characteristics and which take a long-term view over the whole process of closing and replacing institutions.

Where institution costs are currently low, they can be expected to rise due to demands for improved quality of care. Mansell *et al* (2007) note that “if institutional costs rise over time, then decision makers have to be careful about being over-cautious at the outset of the transition process. Dissatisfaction with quality of care in institutions leads to rising costs in institutions over time. For example, the *per diem* costs of public residential institutions for people with intellectual disabilities in the USA, after adjustment for inflation, more than doubled between 1982 and 2002 (Stancliffe *et al.*, 2005). Costs rise because less disabled people are often provided with alternative services first (so the population in institutions includes progressively the most disabled); because more staff are employed in the institutions; and because fewer residents live there in order to try to provide higher quality care. Therefore, cost comparisons that seem to make institutional care less expensive than community care today cannot be sustained in the medium term.”

Once like-for-like comparisons are made, the costs of supporting people with substantial disabilities are usually high, wherever those people live, if good outcomes are to be achieved. Low-cost institutional services deliver low-quality care. There is no evidence that

community-based models of care are inherently more costly than institutions, once the comparison is made on the basis of comparable needs of residents and comparable quality of care. Community-based systems of independent and supported living, when properly set up and managed, deliver better outcomes than institutions.

Policy implications

Ratification of the UN Convention on the Rights of Persons with Disabilities in May 2008 obliges states to develop community living that will replace institutional care. In addressing this task, policy-makers should be aware of the evidence from research that

1. Community living offers the prospect of an improved lifestyle and quality of life over institutional care for people with intellectual disabilities.
2. This applies to old and new institutions, whatever they are called.
3. It is no more expensive than institutional care once the comparison is made on the basis of comparable needs and comparable quality of care.
4. Successful community living requires close attention to the way services are set up and run, especially to the quality of staff support.

Advice and guidance on the establishment of community living is widely available from government and non-governmental organisations. Examples of good practice are available in many countries and technical assistance can be provided through bilateral and multi-lateral arrangements.

However, it is important to note that shifting from institutional to community-based models of care is not simply a case of replacing one set of buildings with another. Successful community-based services need to be carefully planned around the needs and wishes of individual people and then continually monitored and adjusted as people's needs and wishes change. There is a large literature describing 'good practice' in the design and operation of community services. Much evaluative research and comment emphasises the risks that community-based services do not provide sufficiently skilled help for people with complex needs such as profound intellectual and multiple disabilities, challenging behaviour or mental health problems. Implementation lags behind research and development so, although good results have been demonstrated for people with complex needs living in the community, many people with complex needs do not yet receive the help they need to live a good life.

Living well in the community also requires adjustment to a wide range of services available to everyone, so that they are accessible to and effective for people with intellectual disabilities. Here too evaluation and audit often highlights the failure of generic services to respond sufficiently well. As well as changing the training of staff in these services, disability discrimination legislation is being used to require reasonable adjustment for disabled people.

This implies a new agenda for research, concerned more with comparison between the experience of people with intellectual disabilities and people without disabilities than with different kinds of disability service, focusing on all aspects of quality of life and concerned with generic as well as special services.

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