

## **Deinstitutionalisation and community living: An international perspective**

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### **Abstract**

This paper reviews progress in deinstitutionalisation and community living for people with learning disabilities. The effects of replacing institutional care on residents are summarised and some emerging problems identified.

### **Introduction**

Tizard's Brooklands experiment is, in the British context, a defining point of departure for deinstitutionalisation and community living (Tizard, 1960). It was among the earliest attempts anywhere to show that it was possible to care for people with learning disabilities in smaller, more homely circumstances in the community, rather than in institutions. Together with pilot projects in Sweden (Grunewald, 1974) and the USA (Casey et al, 1985), it helped demonstrate that alternatives to institutions were possible at a time when policymakers were receptive to this message. By the late 1960s and early 1970s, the policy goal of deinstitutionalisation – the complete replacement of institutions by services in the community – was articulated (Campaign for the Mentally Handicapped, 1972; Kugel & Wolfensberger, 1969) and then pursued. In North America, Scandinavia, Britain and Australia this has been probably the most important change in policy and the pattern of service provision in learning disability in the last 50 years (Mansell & Ericsson, 1996b).

### **Progress in deinstitutionalisation and community living**

The replacement of large residential institutions by a network of community-based services is well under way in North America, Europe and Australasia. The leaders in this field have probably been Sweden and Norway, which appear to have replaced all institutional provision and enacted laws that enshrine the right to community services (Ericsson, 2002; Tossebro, 2004). For Sweden, for example, Figure 1, opposite,

shows the shift in pattern of services for people with intellectual disabilities over the last 30 years. The data are presented as rates per 100,000 total population to permit international comparison taking account of differences in population size and are taken from Grunewald (2003). All institutions have been closed and replaced with services in the community. In North America, the UK and Australasia, much progress has been made in closing institutions, but continuing efforts are required to complete their replacement by services in the community. Figure 2, below, presents data for the USA (Braddock et al, 1995; Braddock, Hemp & Rizzolo, 2004), showing the same pattern as for Sweden, but at a rather lower level of provision and without the complete abolition of institutions yet being achieved.

Replacing institutions includes the task of closing the last remaining long-stay institutions and the replacement of some of the smaller institutional campuses that were built when the policy of deinstitutionalisation was first promoted. The data for England (DoH, 2004; Mansell, 1997), given in Figure 3, overleaf, show the same pattern as in the USA. In 2004, there were about 750 places left in the old long-stay institutions for people with intellectual disabilities (Ladyman, 2003), but there were also several thousand places in 'campus' developments and new private institutions (DoH, 2004).

The pattern of change in service models in these countries has generally been consistent. Early initiatives to replace institutions produced relatively large residential homes, such as the intermediate care programme in the USA (Rotegard et al, 1984), the Wessex experiment in England (Kushlik, 1976) and the residential home Vårdhem programme in Sweden (Ericsson, 1996). These larger models were superseded by group homes in which between three and eight people, including people needing high levels of support, lived together with help from staff. Demonstration projects of this type include those developed in Andover in England (Felce Et Toogood, 1988; Mansell et al, 19687), Cardiff in Wales (Lowe & de Paiva, 1991), Oregon (Borner et al, 1996), Sweden and Norway (Ericsson, 1996; Tossebro et al, 1996). This is now the dominant form of community provision. More recently, dissatisfaction with group homes has led to the

development of what is generally called 'supported living'. This separates housing and support, so that 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 other European countries, such as Belgium, the Netherlands, Germany, Spain and Greece, community-based services are beginning to be developed, although existing service structures are still dominated by institutional models (European Learning Disability 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 (Mansell, Beadle-Brown & Clegg, 2004).

Evaluation that compares community-based models of care with the institutions they replace generally shows a relatively clear picture.

Research has consistently shown that community-based services are better than institutions. Two recent reviews illustrate typical findings. Kim, Larson and Lakin (2001) reviewed comparative and longitudinal American studies between 1980 and 1999. They found that, in terms of adaptive behaviour:

- \* 19 studies showed significant improvements
- \* seven studies showed improvements which were not statistically significant
- \* one study showed decline which was not significant
- \* two studies showed significant decline.

In terms of challenging behaviour:

- \* five studies found significant improvements
- \* eight studies found improvement that was not statistically significant
- \* six studies found worsening of behaviour that was not statistically significant
- \* two studies found a significant worsening.

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

## Problems of community services

However, this generally positive picture is complicated, because research studies also show marked variation in results. Different services of the same 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, opposite, for example, shows the mean and range of scores for resident engagement in meaningful activity reported in Emerson and Ration's (1994) review of 46 British studies of 2,350 people. It shows that, on average, supported housing achieves better results than small institutions, which in turn achieve better results than large institutions. But the overlap in scores shows 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 supported housing.

This variation undermines the consensus supporting deinstitutionalisation and community living. It removes the powerful incentive that unequivocal evidence would provide. It casts doubt on the value of the investment community services require, by suggesting that congregate care facilities can achieve results as good, even though they provide fewer staff and therefore cost less.

Variation reflects, in part, the range of abilities and characteristics of residents. People with higher support needs – whether because of the nature of their learning and physical disabilities, their challenging behaviour or their social impairment – experience less good outcomes than people who are more independent.

However, variation does not reflect only resident characteristics.

Demonstration projects have shown that it is possible greatly to increase the level of outcomes achieved for the most disabled people (Hatton et al, 1995; Mansell et al, 2001). Variation also reflects characteristics of the design of the services themselves. Most important, it reflects differences in staff performance; 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 et al, 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). This issue can also be traced back to Tizard's work – in this case the study of the features of institutional care published by King, Raynes and Lizard (1971).

Once the material and social deprivation found in institutions has been addressed by replacing them by small-scale services in the community, it appears that 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' [Jones et al, 1996; Mansell, 1998; Mansell et al, 2004]).

Why are community-based services so variable in their performance?

Broadly, two interpretations for this failure have been offered (Mansell & Ericsson, 1996a). Some authors (Ericsson, 1996; Stevens, 2004) have argued that the ideology of institutions persists in group homes and can only be overcome by a further move to supported living. Others have argued that variable results can be seen as a problem of weak implementation (eg Emerson & Hatton, 1994; Mansell, 1996; McGill & Mansell, 1995), rather than something intrinsic to the model. Some support for this view comes from the study by Emerson et al (1999) comparing village communities, dispersed housing schemes and hospital campuses. This study found that dispersed housing (ie supported living), selected for the study as exemplary, achieved no better results than institutional care in resident engagement in meaningful activity.

Better implementation requires a renewed focus on training and the motivation of front-line support staff. This has been an increased focus of attention in the USA (Larson et al, 1998; Rice & Rosen, 1991) and Britain (Great Britain, 2000). However, there is some evidence in Britain that most training covers minimum statutory requirements, such as health and safety, or very basic introductory material (Carnaby 2003; Ward, 1999), and that the motivational framework within which staff work seems to prioritise administration over enabling service users to engage in

meaningful activity and relationships (Mansell [maps to] Elliott, 2001).

The current context for service development

In those countries which have made most progress in deinstitutionalisation and community living, three changes are taking place, to varying degrees. These changes, taken together, provide the context within which the performance of community services is likely to be judged in future. They are:

- \* the rise of market-based approaches to service development
- \* the replacement of special arrangements for learning disability services by generic policies, responsibilities and practices (what is called 'dedifferentiation' (Sandvin, 1996)
- \* a changed perspective on disability which emphasises rights and empowerment, apparently (though perhaps inadvertently) at the expense of addressing the impairments people have.

The rise of market-based approaches to resource allocation and decision-making puts service models in competition with each other. There is less commitment to particular philosophies and models a priori, with increased willingness to judge services on the basis of 'payment by results'. Eligibility criteria are used to ration availability of services. There tends to be a focus on 'value for money', emphasising basic, general, minimum standards as 'good enough', rather than good outcomes for everyone (including those with the highest support needs). Market-based models also entail reduced emphasis on planning, on service models and on locality in favour of 'choice'.

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. Dedifferentiation has also made it harder to identify the special situation of people with intellectual disabilities.

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 have very largely been sustained, in the policy arena, through 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 and tenancy status rather than group homes, in the absence of any evidence at all 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 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 decisionmakers, 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, people representing service user interests and service providers need 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. This implies a much more empirical approach to justifying service development. It means judging services by their results, not by the intentions of those who set them up. It means rediscovering the educational and facilitative role of staff and shaping staff performance through leadership and training. 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.

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