Deinstitutionalisation in Intellectual Disabilities

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Abstract

**Purpose of the review**

As the process of large scale hospital closure comes to an end in England and continues steadily in US, Australia and Ireland, it is just beginning in many other countries within Europe and still a rather vague hope in countries such as Taiwan. This review explores recent literature on deinstitutionalisation and intellectual disabilities and focuses on papers published in academic journals mainly during 2006.

**Recent findings**

Work on deinstitutionalisation continues to show that outcomes are better in the community than in institutional care but recent papers highlight that there is more to deinstitutionalisation than just hospital closure. Just moving people out of institutions into community settings does not bring about automatic improvement in quality of life in terms of choice and inclusion as well as self-identify and access to effective healthcare and treatment. This is especially true for people with more severe intellectual disabilities as well as complex needs such as challenging behaviour. However some of the current research illustrated that even offenders with intellectual disability can be successfully supported in the community.

**Summary**

Recent research provides further examples and lessons on how community care can and should work which it would be hoped will help those countries just starting the process of institutional closure to move more quickly to full deinstitutionalisation.

**Keywords**
Hospital closure, deinstitutionalisation, community care, intellectual disabilities, long-term outcome
Introduction

The number of people with intellectual disabilities in large institutions has been steadily declining in countries such as England [1], the USA [2,3], Canada [4], Norway [5] and Sweden, where no one with intellectual disabilities now lives in institutional settings [6]. Recent research from these countries does not focus so much on the process or effect of deinstitutionalisation as on its long term impact and the challenges of providing good, comprehensive services in the community.

However, there are many countries where the process is less advanced. In Australia, there has been a decline in the number of people in institutional care but there still remain a substantial number of institutional places [4,7]. In Ireland, recent estimates put the number of people with intellectual disability in hospital settings at 3.1% in the Republic of Ireland and 5.3% in Northern Ireland [8], but large residential homes (average number places = 19) and campus settings (average places = 100) are still a common form of provision [9].

In Belgium, The Netherlands, Germany, Spain and Greece, the process of deinstitutionalisation has recently begun but institutional care is still dominant [10]. In other countries, this process is only just starting and in countries such as Hungary, Poland, Romania, the Czech Republic and France there remain large numbers of people in poor quality congregate settings [11,12]. Within Europe there is a determined drive now towards deinstitutionalisation [13] but in some countries the trend is still towards more institutional provision rather than less (e.g. Taiwan) [14].
This review will focus on two main areas in summarising the recent research: first, the long term impact of deinstitutionalisation and challenges to the success of community living; second, the international dimension of deinstitutionalisation research.

**Long term impact of deinstitutionalisation and challenges to the success of community living**

Recent work in this area can be summarised under three headings: the legacy of institutionalisation; the impact of deinstitutionalisation on social inclusion and social networks, self-identity and health care; and the specific situation for people with challenging behaviour.

The legacy of institutionalisation

Hubert and Hollins [15] focused on men with challenging behaviour in a locked institution ward preparing to move into the community. This qualitative study, using mainly participant observation, illustrated that even in recent times in the UK, these people were living a very impoverished existence. Physical and mental health needs were not being adequately met and the dehumanisation of these people in this setting led to little individual, gender or social/family identity. Whilst at the time of writing, the men concerned were still in the hospital ward, the authors concluded that these legacies of long-term institutionalisation, would have substantial effects on the planning process around moving and would persist to the community if not specifically addressed.
The issue of gender identity for people with intellectual disabilities in the community, was also considered by Umb-Carlson and Sonnander [16]. Working in Sweden they explored the gender differences in living conditions for 110 people with intellectual disability and compared these to gender differences in the general population. They found that in general there appeared to be many fewer gender differences in the intellectual disability population than in the general population and concluded that, even in the community, people with intellectual disabilities appear to be treated as “gender-neutral”.

Stancliffe and Lakin [17] found that once people had moved to the community family contact increased, while those who stayed experienced a steady decline in family contact. It is conceivable that for those who have lost contact with family altogether the situation is more difficult to retrieve - once in the community it is not necessarily the case that these people would suddenly increase their levels of social contacts and social inclusion. Hall and Hewson [18] found no change in community links over a 7 year period in community-based settings after moving from hospital. Diaries of outings and of visits from people not paid to be in the home were used to determine frequency and durations of outings/visits. Even in community settings, 88% of the 63 people went out of the home less than once a day. Of those who did go out during the day, 48% went out for less than one hour. Fifty-five percent of people had no personal visits at all in the 4 week period of the study.

Forrester-Jones et al. [19] explored social networks for people in the community 12 years after moving from hospital settings and although this study did not look at changes over time, the authors found that the social networks of the 213 people
involved were largely made up of people related to the service (staff 43% and service users 25%), with on average only 33% of members not related to the services in which people live – 14% were family members and 11% were social acquaintances and friends. The remainder were contacts working in shops, pubs etc. These findings are consistent with earlier work looking at the effect of deinstitutionalisation on social networks which found that whilst the process of deinstitutionalisation helped people to have larger social networks, these were not necessarily more inclusive [20, 21].

**Achieving the aims of deinstitutionalisation in community care settings**

Recent studies illustrate to some extent the challenges of community care and in particular to the achievement of the aims of deinstitutionalisation, including increased social integration and participation, valued roles and an “ordinary life” and individualised support.

Abbot and McConkey [22] conducted focus groups with 68 people with intellectual disabilities who lived in supported living or shared group homes in Northern Ireland. They explored the barriers to social inclusion and the solutions as perceived by the people themselves. There were 4 main sets of barriers identified including personal abilities and skills, staff management of inclusion (e.g. allowing and supporting people to go out), the location of the house within the community (and access to transport etc) and community attitudes and the facilities available in the community.

McConkey, Abbot, Noonan-Walsh et al. [9], took a more quantitative and comparative approach to social inclusion of people with intellectual disabilities in Ireland and used a key worker questionnaire to obtain information on social inclusion for 620 people living in 5 different settings across the whole of Ireland. Comparisons
were made between dispersed supported living (n = 103, 41% of those living in this type of setting), clustered supported living (n=132, 88%), small group homes (n=152, 4%), residential homes (n=138, average size 19 places, 17%) and campus settings (n=95, average size was 100 on each site, sample represented 2% of those living in this type of setting). Social inclusion was generally lower in campus settings than in any other setting. Those in campus settings were more likely to have had a visit to or from the family and to have stayed away overnight and to have been to church, but those in clustered supported living followed by dispersed supported living had better social inclusion than other settings.

Severity of intellectual disability has been shown to differentiate quality of life for people with intellectual disabilities in the community. Those who are more severely disabled tend to experience less social inclusion, meaningful activity and less choice. Smith, Morgan and Davidson [23] explored daily choice availability for 59 people with intellectual disabilities living in 16 group homes in Tasmania and found that whilst those with mild intellectual disability did not differ significantly from those without disabilities, those with severe intellectual disabilities experience many fewer opportunities for choice.

Finally, Beadle-Brown, Mansell, Whelton et al. [24] illustrate that institutionalisation and the resulting social isolation and loss of family contact sometimes impacts not only on the quality of life of people and the quality of planning possible as they move into community settings but also on the location and quality of placements. They explored the reasons for and effects of placements for people with intellectual disabilities made outside the local area in England. People placed out-of-area
experienced less opportunities for choice, less social inclusion and lived in homes meeting fewer of the national minimum standards than in other studies.

The impact of deinstitutionalisation

Hallam, Beecham, Knapp et al [25] (2006) explored service use and costs of support for over 250 people with intellectual disabilities 12 years after moving into the community. They found that the cost of care in community settings was still higher than it had been in hospital but that it was getting lower and was less than it had been at 1 year and at 5 years after deinstitutionalisation. People were living in a variety of settings from residential care to independent living. There was no relationship between cost and outcomes although people had a better quality of life in the community than they had had in the institutions.

Young [26] followed 30 matched pairs of people with severe intellectual disability and challenging behaviour 12 and 24 months after they had moved out of institutional care into either dispersed housing in the community (each with 2-3 places) or cluster centres (usually 7 or 8 houses catering for 20-25 people in total with an administration centre on site). Consistent with earlier research on deinstitutionalisation, both groups increased in adaptive behaviour, choice making and general quality of life. There was no change in the level of challenging behaviour. However, they did find some differences between service types, with those in the dispersed community settings showing greater increases in particular adaptive behaviour domains (domestic activity and responsibility), choice making and general quality of life.
The area of impact most analysed recently has been the effect of deinstitutionalisation on health care – both access and quality. With deinstitutionalisation there was increasing demand on general practitioners and other mainstream medical professions, to cater for the health needs of people with intellectual disabilities. However, issues of access to mainstream health services, the lack of training for health care professionals and problems of co-ordination between healthcare professionals has been well documented - both the issues and suggestions for more integrated care provisions are reviewed by Jansen, Krol, Groothoff and Post [27].

Attempts to improve healthcare provision for people with intellectual disability, have usually focused on training of healthcare professionals. Melville, Cooper, Morrison et al [28] found significant increases in the knowledge of healthcare professionals after a training programme specifically designed for the purpose. However, there remains no research as to whether such training has an effect on the actual experience of people with intellectual disabilities and Melville et al suggest that this should be the next step in research in this area. However a different approach was taken by Lennox, Rey-Conde and Cooling [29] working in Australia. They used a comprehensive health assessment programme (CHAP) to guide GPs in conducting a full health review for 25 people with intellectual disability following their move to community care. The review identified health needs for all but one of the people and resulted in medication review for almost 50% of people. The authors concluded that a comprehensive health check by the new GP at the time of deinstitutionalisation would help to build the relationship with the GP and ultimately result in a better experience for people in the community.
The “special” challenge of challenging behaviour

Those with challenging behaviour (and in particular offending behaviour) or mental health problems are the most likely to continue to live in institutional services (either in hospital or in secure units) and to have a poorer quality of life. They are also more likely to be re-institutionalised after the move to community care. Alexander, Crouch, Halsted and Piachaud [30] followed up 24 people discharged from a medium secure unit between 1987 and 1993 and a further 37 discharged between 1994 and 2000 and found that 11% were reconvicted and 28% were currently detained in hospital under the Mental Health Act. Craig, Stringer and Moss [31] illustrated, however, that it does seem possible to support sexual offenders to live in community settings through treatment groups, although suggests that distinguishing the effect of the treatment group from other management strategies is extremely difficult. Hall, Parkes, Samuels and Hassiotis [32] illustrated that people with intellectual disabilities and mental health needs could be effectively supported in the community and could achieve similar outcomes with regard to improved psychiatric status when supported in the community. Riches, Parmenter, Wiese and Stancliffe [33] report that in Australia services are either for people with intellectual disabilities or people with mental health needs – they are not designed to cope with people who have a dual diagnosis. They describe two small scale programmes to support people with intellectual disabilities and mental health needs in the community. The first was a system of case management for people on release from prison but barriers to successful implementation were numerous. The other provided both accommodation and therapy for three men who had been sexual offenders. Although clinical changes were relatively limited and the need for ongoing supervision and support remained
substantial, none of the men had reoffended since entering the unit and quality of life for the men increased.

Another issue pertinent to the management of challenging behaviour in the community is the use of psychotropic medication. McGillivray and McCabe [34] examined the relationship between residence and pharmaceutical management of behaviour in a large sample of people in different settings at two different time points and found that the proportion of people with prescribed medication was not different between institutional and community care but the prescriptions were slightly more used in institutional settings. Over time the pattern has changed – previously those in institutions were receiving more medication than those in the community but this had evened out over time. The main conclusion drawn by McGillivray and McCabe is that deinstitutionalisation does not necessarily lead to reduced use of psychotropic drugs to manage behaviour.

**New reflections on process and outcomes**

The second, smaller, stream of recent publications in this area has focused on the lessons learnt on the process of deinstitutionalisation from an international perspective and the challenges for those starting the process of moving to community care.

Mansell [1] takes a broad international approach to the analysis of the process and outcomes of deinstitutionalisation and the priorities for the future development of community-based services. The main changes which are identified as having had an impact on the implementation of deinstitutionalisation include the rise of market-
based approaches to service provision, arrangements for rationing services, the “de-differentiation” of intellectual disability services, and the rise of a rights-based model in disability policy. The paper sets out priorities for the future development of community services, arguing that 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 the role of staff to provide more facilitative, enabling support of individuals, especially those with the most severe or complex needs. Bigby and Fyffe [35] focus on whether institutional closure equates to deinstitutionalisation. They present a brief description of the process involved in closing two small (58 and 100 place) institutions in Victoria State, Australia and draw out the lessons learnt from the process. Firstly, they found that there was a tension between the management of the closure process and the need to keep the focus on individuals. They found a group based approach to planning with sharing housing for 4-5 people. Houses were built to standardised designs and there was a reluctance to adapt to individuals. People were moved to live together with no choice about who they lived with. Secondly, Bigby and Fyffe describe conflict between the needs of staff and the needs of service users. Much of the reprovision in these cases was designed around staff to make it easier for them to get to work, move from one service to another etc. Because existing staff left for other jobs in order to ensure their own job security, new staff did not have adequate handover arrangements, thus impoverishing the experience of service users as they made the transition. Although transition plans were made for each service user, these were often disrupted by organisational imperatives and the plan not followed. Thirdly, a culture of engagement in meaningful activity at home and in the community was not created as job descriptions focused on the day to day management in the home and there was little preparatory work done to
prepare the community for the people moving out. Finally, a focus on improved environment and financial viability obscured any focus on improved quality of life. In conclusion Bigby and Fyffe suggest that there is much more to deinstitutionalisation than just closing an institution and without attention to the areas described above, the danger is that the new services will just be smaller institutions located within the community.

Vann and Siska [12] focus on the Czech Republic where the process of deinstitutionalisation is only just starting. Some NGOs offer community alternatives to the large institutional services but demand for these far outweighs supply. Vann and Siska review the situation of people with intellectual disabilities and report on the state of institutions in the Czech Republic. They also consider the barriers to deinstitutionalisation in the Czech Republic including the current legal and political structures. Despite recent attention to the unacceptable conditions of many institutions in CEE and other countries, there persists a lack of motivation for policy makers to push this agenda and thus there is a lack of instruments and methods available to start the process. Vann and Siska report that although it looked liked some of the much needed momentum in this respect was starting to build, this was hindered further in 2005 by the an amendment to the law on social care which legalised the use of restraints, including cage beds, in social care institutions.

**Conclusion**

McConkey [36] concluded in his review on community care and resettlement that “although the demise of institutional care is not complete, its condition is probably
terminal”. Whilst in England and Scandinavia hospital settings for people with intellectual disabilities have all but closed and in the USA and Australia there have been substantial numbers of hospital closures, there remain challenges to full deinstitutionalisation even in these countries. People living in community settings still experience institutional practices and attitudes and can lead lives that are predominantly devoid of choice, independence and inclusion. As new mechanisms such as self-directed support and personal budgets are established in countries where community care is the norm, it will be essential to ensure that these are well evaluated and the lessons learnt made available for others who are just starting on the process of deinstitutionalisation. There is also the challenge of stopping re-institutionalisation and promoting effective support and treatment for those with more complex needs such as challenging behaviour.

As European initiatives to bring about deinstitutionalisation take effect one might expect future research to feature a resurgence of papers on the process and impact of deinstitutionalisation in poorer countries such as those in Eastern Europe. It will be interesting to see the route these countries choose to take – whether they will move straight to the new paradigms of self-directed support, supported living and personal budgets, saving themselves perhaps three decades by applying the lessons learned from other countries or whether they will decide to take a more incremental approach, learning from their own experience as they go.

References
Papers of particular interest, published within the period of review (Dec 2005 to Jan 2007) have been highlighted as:
* of special interest
** of outstanding interest

Although this paper does not present new data, it is a really useful analysis of the process and outcomes of deinstitutionalisation and the priorities for the future development of community-based services from a broad international approach. It provides useful


This brief paper provides figures for the number of people still in large state facilities in the US and traces the trend towards deinstitutionalization across all US states.


A study on the prevalence of intellectual disability in the Republic of Ireland and Northern Ireland with some figures on residential arrangements and implications for service planning.


A quantitative study of the social inclusion and social competences of persons with intellectual disabilities using different types of residential services. As well as giving information on social inclusion it also provides useful figures of the types of services available in Ireland.


A description of the characteristics and legacies of residential care systems in post communist transition countries and a review of progress towards community inclusion and deinstitutionalisation in the Czech Republic.


A thorough review of trends in residential services for people with intellectual disabilities in Taiwan from 1982 to 2005 based on a postal survey with service providers.

Qualitative study using ethnographic methods to describe the life of 20 men with severe learning disability and challenging behaviour in a locked hospital ward.

Survey of gender differences in the living conditions of people with learning disabilities and a comparison with differences observed in the general population in Sweden.

This article presents the results of a longitudinal study on the frequency and stability of family contacts of two groups of institutionalised persons; one of them relocating to community settings and the other staying in the institution. It is one of the few studies from the review period which actually reports the effects of deinstitutionalisation.

This brief report describes a study measuring the community inclusion and participation of people with intellectual disability living in residential homes in England in 1995 and 2002. Although a very simple study in design, it provides a clear illustration of the difficulties of achieving true deinstitutionalisation.


This is a study of a cohort of over 100 individuals who moved to community settings from institutions. It explores the size and type of their social and support networks, and also compares these networks across different types of community settings.


This article reports on a qualitative survey that investigated how people with learning disabilities perceive their social inclusion using focus groups with participants living in community settings in Northern Ireland. It is useful in that it illustrates the issues from the perspective of people with intellectual disabilities themselves and provides some solutions for improving social inclusion.


This study explores the daily choice-making opportunities of people with intellectual disabilities living in small community settings and compares them to those of the general population in Australia.


A quantitative study on the practices and impact of placing people with intellectual disabilities in residential services away from their home area in England.

This study investigates whether and how service-use patterns and costs have changed more than a decade after resettlement in the community. It is one of the few recent studies which focuses on the longer-term outcomes of deinstitutionalisation.


A study of two matched groups of 30 adults with moderate and severe intellectual disabilities and challenging behaviour on the impact of moving from an institution to dispersed and clustered community housing in Australia.


The evaluation of training interventions designed for primary health care professionals aiming to improve access of people with intellectual disabilities to services.


This study investigates the impact of a specifically designed, structured health review procedure (CHAP = Comprehensive Health Assessment Programme) on the health of people with intellectual disabilities during transition from institution to the community. Although a small scale study it provides a useful illustration of a potentially effective structure to improve healthcare access on the move to the community.


A follow-up study of two cohorts of individuals discharged from medium-secure intellectual disability services between 1987-93 and 1994-2000 reporting on the clinical and long-term outcomes.


A description and a critical review of a 7-month treatment programme for 6 persons with intellectual disability and a history of sexual offending.

The study presents and compares the clinical outcomes of an inpatient and a community service unit of a specialist mental health service for people with intellectual disabilities with mental health needs.


This relatively small scale study reports the results and experiences of a prisoner release project and a model provision project designed to support people with intellectual disability in the criminal justice system in Australia. It provides an illustration of how offenders with learning disabilities can be supported in the community.


This is a cross-sectional and longitudinal analysis of the relationship between the type of residential setting and drug administration to manage challenging behaviour in Australia.


Using two case studies from Australia this study explores some of the latest policy challenges and dilemmas arising from the tension between closure of institutions and deinstitutionalisation. It provides useful lessons to inform the process of deinstitutionalisation in the future and in other countries.

36 McConkey R. Community care and resettlement, Curr Opin Psychiatry, 2000; 13: 491-495