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# DEINSTITUTIONALISATION IN AUSTRALIA PART I: HISTORICAL PERSPECTIVE

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## Introduction

Dispersed housing in the community has been shown to be a preferable alternative to large institutions for improving quality of life for many people with intellectual disability. The outcomes of deinstitutionalisation have been reported in literature reviews undertaken in the United Kingdom (UK) (Emerson and Hatton, 1996), United States (US) (Kim *et al.,* 2001; Larson and Lakin, 1989) and Australia (Young *et al.,* 1998). Despite widespread acceptance of deinstitutionalisation policies and practices, it was believed that people with severe and profound levels of intellectual disability, medical complications, those of older age, and/or having severe challenging behaviour were manageable only in institutions even though substantial gains in adaptive behaviour, especially involving social adaptation, have been highlighted when these people are placed in a supportive environment in a community setting.

Based on the principle of normalisation (Nirje, 1985), deinstitutionalisation has dominated the development of services for people with intellectual disability in many western countries (see e.g. in the US Anderson *et al.,* 1998; Kim *et al.,* 2001; Lakin *et al.,* 2000; Maisto and Hughes, 1995; in the UK Emerson *et al.,* 2000; Emerson and Hatton, 1996; and in Europe Hatton *et al.,* 1995; Holt *et al.,* 2000). Fewer individuals with intellectual disability are being accommodated in large public residential facilities with a concurrent increase in the number in community group homes including those for residents with severe intellectual disability. In Australia, large scale deinstitutionalisation began about 20 years later than similar movements in North America and Europe. It involved residential relocation of people with intellectual disability into geographically dispersed group houses with five or fewer residents serviced by community support staff (Ashman *et al.,* 1991). This contrasts with the experience in the UK or US

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where people with intellectual disability moved from large institutions to purpose built 20-24 place hospitals, community units, or cluster housing as well as homes in the community.

Results from deinstitutionalisation research highlight specific changes that have occurred in the areas of adaptive and maladaptive behaviour, choice-making, quality of life issues, and longitudinal outcomes. Adaptive behaviour improves generally across age and ability groups after relocation from the institution (see e.g. Fernando *et al.,* 1997; Heller *et al.,* 1998a), although most recently Stancliffe *et al.* (2002) reported decline in adaptive behaviour for long-term institutionalised residents in congregate centrebased care and no change for those in the community group. Some general findings related to adaptive and maladaptive behaviour, choice-making, and objective quality of life are presented below and include references with adequate sample size and robust experimental methodology.

*Adaptive behaviour.* Positive changes in adaptive behaviour and quality of life have been reported in numerous studies (see e.g. Dagnan *et al.,* 1998; Felce and Repp, 1992; Heller *et al.,* 1998b; Knobbe *et al.,* 1995; Lister Brook and Bowler, 1995; Lord and Pedlar, 1991). Other research teams have reported improved lifestyle factors including material standard of living, physical living conditions, and variety and stimulation in the physical environment (see e.g. Emerson and Hatton, 1996; Heller *et al.,* 1998a; Janssen *et al.,* 1999; Nottestad and Linaker, 1999). Other studies have reported that over time in the community there was a plateauing of adaptive behaviour gains, levelling out of community skills and home leisure activities, limited contact with people without intellectual disability and programmes often emphasised quantity of activity rather than quality (see e.g., Cullen *et al.,* 1995; Dagnan *et al.,* 1998; Lister Brook and Bowler, 1995; Lord and Pedlar, 1991; Stancliffe *et al.,* 2002). In fact for many of these residents life in the community was no better than life in the institution.

*Maladaptive behaviour.* One of the arguments against the implementation of deinstitutionalisation is the belief that challenging behaviour will increase. Researchers have reported both reduced or increased levels of maladaptive behaviour (c.f. Cullen *et al.,* 1995; Felce and Repp, 1992; Fine *et al.,* 1990). Most studies comparing levels of maladaptive behaviour after relocation from the institution to the community report no change (Heller *et al.,* 1998a; Kim *et al.,* 2001; Larson and Lakin, 1989; Young *et al.,* 2001). Reduced access to mental health services and behavioural specialists has been cited as a reason for increased levels of challenging behaviour (e.g. Fernando *et al.,* 1997; Nottestad and Linaker, 1999).

*Choice-making*. Increased opportunities for choice-making and expressing preferences have been reported in community homes following deinstitutionalisation (see e.g. Conroy, 1996; Lister Brook and Bowler, 1995; Stancliffe and Abery, 1997; Stone, 1990; Tossebro, 1995). Increased decision-making and more opportunities for self-determination are also commonly reported (Heller *et al.,* 1998a; Janssen *et al.,* 1999). However, Dagnan *et al.* (1998) noted reduced opportunities for choice-making by residents after 41 months of community living due to the implementation of regular routines and staff familiarity with residents. There appear to be few differences in opportunities for self-determination between community homes and institutions.

*Objective Life Quality.* Some of the benefits of community living are reflected by objective positive changes in life quality in

community participation in terms of access to local facilities and diversity of recreation, leisure and social activities (see e.g. Dagnan *et al.,* 1994; Felce, 1998; Janssen *et al.,* 1999; Knobbe *et al.,* 1995; Nottestad and Linaker, 1999), social networks (Knobbe *et al.,* 1995; Lord and Pedlar, 1991; Stancliffe and Lakin, 1998, 1999), activity levels (De Kock *et al.,* 1988; Felce and Repp, 1992; Jones *et al.,* 1999), health (Conroy and Adler, 1998; Dunt and Cummins, 1990; Heller *et al.,* 1998a; Heller *et al.,* 1998b; Lord and Pedlar, 1991), staff:resident ratio (Felce and Repp, 1992; Lister Brook and Bowler, 1995; Stancliffe and Lakin, 1998). In addition, several writers have also drawn attention to the more effective provision of services leading to lower cost than was the case when residents were living in institutions (Beecham *et al.,* 1997; Knobbe *et al.,* 1995; Stancliffe and Lakin, 1998). However, maintenance of positive outcomes is not always guaranteed over the longer term.

### *Longitudinal outcomes of deinstitutionalisation*

Support for the long-term benefits of deinstitutionalisation and its contribution to improved quality of life have been reported in the literature in North America and the United Kingdom (e.g. Ashaye *et al.,* 1998; Edgerton *et al.,* 1984; Fernando *et al.,* 1997; Fine *et al.,* 1990; Lowe *et al.,* 1993; Schalock, 1986; Stancliffe and Lakin, 1999). However some early longitudinal studies reported that gains in skills or lifestyles were not maintained over the longer term (see e.g. Atkinson *et al.,* 1980; Hemming *et al.,* 1981).

Many dependent measures, including the Adaptive Behaviour Scale (ABS) (Nihira *et al.,* 1993) have been used to examine differences between institutions and community residential settings and have generally shown increased adaptive behaviour scores after relocation (Felce and Repp, 1992; Lowe *et al.,* 1993). However, some researchers have reported no changes in ABS scores when comparing institution and community residents. Initially, there were small increases that levelled out over time with little subsequent improvement (Cullen *et al.,* 1995; Felce, 1998; Lowe *et al.,* 1998). Similarly there have been few large longitudinal studies following the entire adult population of an institution for up to two years post-institution notwithstanding Stancliffe *et al.* (2002). Such studies of deinstitutionalisation in Australia have likewise been limited.

### *Deinstitutionalisation in Australia*

There have been three comprehensive studies of deinstitutionalisation in Australia. In Victoria, the closure and relocation of residents from a small institution - St Nicholas Hospital - was documented in a number of studies (Cummins, 1993; Cummins and Dunt, 1988, 1990; Cummins *et al.,* 1990a, 1990b; Dunt and Cummins, 1990). After four years out of the institution young adults (the oldest was 21 years when leaving the institution) and children with severe and profound intellectual and multiple disabilities showed developmental gains of 2-3 years in adaptive skills, increased leisure activities, and family contact, and showed no change in health or mortality rates. Their life quality in the community was substantially improved over what would have been expected had they remained in the institutional conditions of the hospital.

The effectiveness of deinstitutionalisation was evaluated after 12 months on people with intellectual disability moving

from hostels or a state-run institution in New South Wales into community group homes. Molony and Taplin (1990) reported increased functioning for those people living in the community compared with those who remained in the institution. Community living had a positive effect on the acquisition of adaptive skills and overall quality of life.

The outcome of relocation of adults with intellectual disability from a large, state-run institution in Victoria into community houses or smaller group residences was reported by Owen *et al.* (1994) and compared to a control group who remained in the institution. Those who left the institution showed increased activity levels and skills, empowerment in decision and choice-making, community integration, and improved quality of care. These studies were undertaken over ten years ago and it is questionable whether the sociopolitical circumstances that existed then would have the same impact as today.

### *Institutional reform*

In 1993 the government of the day in the state of Queensland decided to embark on a process of institutional reform involving the closure of all state run institutions for people with intellectual disability and relocation into homes in the community under the auspices of person-centred planning (Mount, 1987). The largest institution in the state - Challinor - was closed permanently in 1998 and all its residents relocated into either community or centre-based accommodation provided by both the government and private sector. Their decision in favour of either option was made by the residents following meetings with other family members, staff, service providers, and the legal guardian when residents did not have any family contact. Transition usually involved orientation visits to the new home with service staff, and perhaps an overnight stay, but once residents moved they did not return to the institution as it was to be permanently closed.

The outcomes in terms of adaptive behaviour, choice-making, and objective life quality for the 104 residents who chose the community based option are reported in detail in Part II. A succession of ministers and changes in government from 1994 to 1997 coupled with family, staff, and public dissatisfaction about the lack of centre-based care resulted in the establishment of two congregate care accommodation centres in the north and south of Brisbane. The congregate care facilities house up to 25 residents and are built along cluster housing model lines. They contain detached houses, duplexes (two houses joined), and an administration centre, and are operated by the government sector. Long-term outcomes for the residents relocated to centre based care are not yet available owing to delays in the relocation process.

## Summary

Research reported in this literature review of deinstitutionalisation from an international and Australian perspective has demonstrated variable changes in adaptive behaviour and residential satisfaction related to living in the community compared with institutional living for most people with intellectual disability. A number of negative factors associated with deinstitutionalisation have been reported with some community residential services providing a quality of life similar to institutions (Emerson and Hatton, 1996). It cannot be assumed that every occasion of

relocation will automatically result in improved outcomes for residents and it is questionable whether changes in adaptive and maladaptive behaviour are maintained uniformly over the longer term following deinstitutionalisation. There is also a lack of research highlighting the effects of deinstitutionalisation for those who are aging, have severe levels of intellectual disability and have been institutionalised long-term. These people are the focus of a research project described in Part II.

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