



Disability Research Series **11**

Supported Accommodation Services for People with Intellectual Disabilities:

A review of models and instruments used to measure quality of life in various settings



National Disability Authority
Údarás Náisiúnta Míchumais

Executive Summary

Summary

In 2005 the National Disability Authority commissioned research on the quality and costs of supported accommodation for people with intellectual disabilities. This document is a summary guide to the final report “Supported Accommodation Services for People with Intellectual Disabilities: a review of models and instruments used to measure quality of life in various settings” which was published in 2008.

This summary briefly presents research findings from a review of research conducted between 1995 and 2005 examining the impact of deinstitutionalisation on residents with intellectual disabilities; specifically in terms of independence, civic participation and well-being. The comparative costs and benefits associated with different models of residential provision are also reviewed. The report concludes that while there is some evidence to suggest that smaller, less institutionalised settings are associated with greater levels of choice, self determination and participation in community and social activities, there is no systematic evidence to suggest that larger or more institutionalised settings are associated with better quality of life outcomes. Copies of the full report are available from the National Disability Authority.

Background

In 2005 the National Disability Authority commissioned a consortium of researchers from Ireland, the United Kingdom (UK) and the United States of America (USA) to examine the quality and costs of supported accommodation for people with intellectual disabilities. While differences exist among the types of residential services that are termed ‘supported accommodation’, this report defines supported accommodation as comprehensive residential services provided in small group home settings.

At the time of publication, over six thousand adults with intellectual disabilities were receiving residential services in Ireland. Similar numbers of adults were identified residing in small scale

community-based group homes to those residing in larger non community-based residential centres. As the move towards community-based residential services continues to grow in Ireland, there is continuing debate about the advantages associated with different types of residential settings.

It is timely therefore to review the international evidence base on the quality of outcomes for people with intellectual disabilities living in different types of residential settings. Outcomes are defined as all aspects of the life experiences of people with intellectual disabilities living in different forms of supported accommodation that can be directly linked to that person's quality of life.

The research undertaken by the consortium comprised three elements:

1. A review of deinstitutionalisation and post-deinstitutionalisation research conducted between 1995 and 2005
2. An examination of the comparative costs and benefits associated with different approaches to providing supported accommodation
3. An examination of the instruments used to measure outcomes for people with intellectual disabilities who receive residential support services (This element is not reviewed in the present document; details can be found in the full report)

1. Review of deinstitutionalisation and post-deinstitutionalisation research conducted between 1995-2005

A total of 67 research studies were identified for review, most of which were carried out in the UK or the USA. The review includes two types of research studies; deinstitutionalisation and post-deinstitutionalisation.

Deinstitutionalisation studies evaluate the impact of the replacement of large state-run institutions by smaller less restrictive settings on the quality of life of people with intellectual disabilities.

Post-deinstitutionalisation studies evaluate the impact of different types of community-based residences on quality of life. Community-based residences include group homes (e.g. a 24-hour staffed home in the community), supported or semi-independent living (e.g. independent accommodation with limited support from paid staff) and campus/cluster-style settings (e.g. a number of living units forming a separate community from the surrounding community).

Findings from these studies were examined across three key themes: 'independence', 'civic participation/social inclusion' and 'well-being'. A brief summary of the overall findings from these studies is presented below:

What, if any, evidence is available regarding the impact of deinstitutionalisation and post-deinstitutionalisation on the 'independence' of residents?

- There is consistent evidence that the personal skills of people with intellectual disabilities typically improve immediately following deinstitutionalisation
- Greater levels of choice and self determination are observed following deinstitutionalisation across a range of community-based settings. Typically, smaller and more independent residential options promote choice and self determination
- Evidence of the impact of deinstitutionalisation on levels of engagement in domestic activities is mixed, with some studies reporting significant increases following deinstitutionalisation and others reporting no change in activity
- There is strong evidence that level of engagement in domestic activity is related to residents' characteristics (e.g. skill/adaptive behaviour) and staff behaviour. When these factors are taken into account, the association between residential setting and engagement in domestic activity is weak
- Improvements in personal skills tend not to continue to develop over time. However, when observed, these improvements are associated with smaller dwellings

What, if any, evidence is available regarding the impact of deinstitutionalisation and post-deinstitutionalisation on the ‘civic participation/social exclusion’ of residents?

- Deinstitutionalisation is associated with increases in social networks and relationships
- Community-based, smaller, and more independent settings are associated with more extensive social networks and relationships
- Participation in community-based activities is enhanced following deinstitutionalisation
- Evidence suggests that campus-type settings and cluster housing (defined as a number of living units forming a separate community from the surrounding community) offer a poorer quality of life than dispersed community-based options
- Greater levels of engagement in community-based activities are associated with residents’ characteristics. When controlling for the effects of residents’ characteristics, residents of more independent type settings and community-based settings reported increased levels of participation in activities
- Higher levels of satisfaction with social networks and relationships have been reported for residents with semi-independent living arrangements when compared with residents of group homes, and for residents of intentional communities (e.g. commune-style accommodation based on a common social, political or spiritual vision such as that provided by L’Arche or Camphill Communities) when compared with community-based residents
- Few studies have examined the relationship between residential setting and employment. The limited available evidence suggests a weak relationship between residence and employment levels

What, if any, evidence is available regarding the impact of deinstitutionalisation and post-deinstitutionalisation on the ‘well-being’ of residents?

- Personal life satisfaction increases following deinstitutionalisation
- Following deinstitutionalisation, levels of satisfaction are consistent across a range of residential options including community-based housing, intentional communities and group homes
- There is limited evidence to suggest that residents of community-based settings are more likely to engage in physical activity than those residing in non community-based settings
- A small number of studies have reported mixed findings regarding the impact of deinstitutionalisation on physical health and mortality
- Studies investigating the relationship between deinstitutionalisation and emotional well-being/mental health report mixed findings, with the majority indicating that deinstitutionalisation is not associated with changes in well-being/mental health

This evidence is presented in tabular format in Appendix I at the conclusion of this report. The table classifies these findings according to whether they emanated from deinstitutionalisation or post-deinstitutionalisation studies.

In addition to those studies above which have focused on specific quality of life domains such as independence, civic participation/social exclusion and well-being, a small number of studies have examined the influence of a person’s residential setting on their overall quality of life (as opposed to specific quality of life domains). These studies have reported:

- deinstitutionalisation is associated with increased quality of life
- increased quality in small to medium sized organisations
- increased quality in more independent settings for people with less severe intellectual disabilities

- increased quality in community-based residences when compared to campus-style or cluster housing
- increased satisfaction with living arrangements in which staff management practices are more highly organised
- an ‘aggressive-defensive’ management style and organisational culture is associated with lower quality in community-based residences

2. An examination of the comparative costs and benefits associated with different approaches to providing supported accommodation

Few studies have examined the relationship between the costs of different forms of supported accommodation for people with intellectual disabilities. The limited evidence suggests:

- There is a strong relationship between residents’ characteristics and associated costs
- Studies comparing the costs of post-deinstitutionalisation residential options indicate that lower costs were observed in semi-independent settings when compared with group homes
- Lower costs have also been observed in campus and cluster-style housing when compared with community-based options
- Higher costs were observed in community-based settings for people with challenging behaviour when compared with institutionalised settings
- Higher costs were also observed for services in more congregate settings for people with challenging behaviour and dual sensory impairment when compared with non-congregate settings

Conclusions

There are few studies on the quality and costs of supported accommodation for people with intellectual disabilities in Ireland. Internationally, research gaps in this field suggest further research is required to:

- examine particular outcomes such as material circumstances and employment
- examine particular types of supported accommodation such as supported living
- examine specific groups of residents such as those with more severe levels of disability
- examine determinants of quality, such as poverty and the organisation culture within which staff operate
- promote participatory approaches to research by including persons with intellectual disabilities themselves in the research process

Appendix I

**Table I: Supported Accommodation & Quality of Life
Core Dimensions**

Independence		
	Deinstitutionalisation Studies	Post-Deinstitutionalisation Studies
Personal skills	Relatively consistent evidence of limited improvements in personal skills immediately following deinstitutionalisation.	Few studies. Some evidence of increased skills in smaller, less institutional settings.
Material well-being	Little evidence.	No evidence.
Choice and Self-Determination	Consistent evidence of greater choice and self-determination in community-based settings.	Consistent evidence that greater choice and self-determination is available in smaller, less institutional settings.
Other	Some evidence of increased participation in domestic activities following deinstitutionalisation.	Little evidence of association between the nature of setting and engagement in domestic activity. Strong evidence that engagement is related to personal skills of participants and staff activity.

Table 2: Supported Accommodation & Quality of Life Core Dimensions

Civic Participation/Social Inclusion		
	Deinstitutionalisation Studies	Post-Deinstitutionalisation Studies
Social networks and friendships	Consistent evidence of greater participation in social networks/relationships in community-based settings.	Evidence inconsistent, but suggests that larger and/or more active social networks are available in smaller less institutional settings.
Community-based activities	Consistent evidence of greater participation in community-based activities in community-based settings.	Consistent evidence that greater participation in community-based activities occurs in smaller less institutional settings.
Employment	Little evidence.	Little evidence, but suggests no relationship between type of setting and employment.

**Table 3: Supported Accommodation & Quality of Life
Core Dimensions**

Well-being		
	Deinstitutionalisation Studies	Post-Deinstitutionalisation Studies
Emotional well-being/mental health	Considerable evidence of no systematic association between deinstitutionalisation and emotional well-being, mental health or challenging behaviour.	Little evidence. No consistent pattern.
Physical health	Little evidence. Conflicting reports of possible association between deinstitutionalisation and increased mortality.	Little evidence. Some suggestion of increased rates of physical exercise in smaller less institutional settings.
Personal life satisfaction	Consistent evidence of greater satisfaction in community-based settings.	Little evidence, but suggests no relationship between setting and personal life satisfaction.
Other	N/A	Little evidence. No consistent pattern.



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