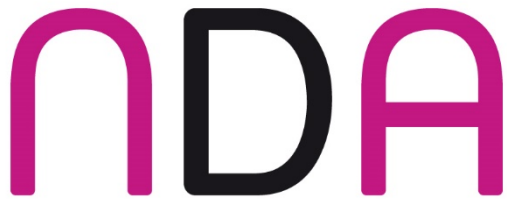


# **MOVING TO COMMUNITY LIVING**

## **A Contemporary Developments in Disability Services Paper**

This document comprises one element of a wide-ranging and ongoing body of work being undertaken by NDA in the field of Independent and Community Living for people with disabilities



**Údarás Náisiúnta Míchumais  
National Disability Authority**

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## MOVING TO COMMUNITY LIVING

This document comprises one element of a wide-ranging and ongoing body of work being undertaken by NDA in the field of Independent and Community Living for people with disabilities.

In 2005, for example, NDA commissioned a systematic 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. A publication of this review is now available on request from NDA. More recently, the NDA Research Promotion Scheme for 2009-2011 has been launched and invites researchers to apply for funding under the theme Promoting Independent and Community Living for People with Disabilities. NDA has also examined recent research literature on the process of deinstitutionalisation in Europe.<sup>1</sup> NDA is also currently exploring methodologies used to determine the cost of residential provision for people with disabilities and recommendations on how such costs may be determined in future research. This document combines NDA's progress to date on examining these latter two strands of research: deinstitutionalisation in Europe and cost methodologies.

Key recommendations from the study of deinstitutionalisation in Europe by Mansell *et al.*, (2007) were:

- The role of Government at national and regional level is central to providing a vision for change. A comprehensive vision for community options can incorporate incentives for change and promote positive demonstrations of good practice. Legislative support for inclusive practices should be encouraged.
- Stop building new institutions and spend the majority of available funds to develop services in the community
- Institutional settings should be required to permit site visits and encouraged to promote community services. Inspections to evaluate living conditions and quality of life should be undertaken. The results from inspection visits should be open to public scrutiny and redress.
- Innovative services, such as supported living, should be promoted as models of best practice and evaluated for quality and cost. Residents of all levels of ability should be encouraged to participate in new service developments.
- Mechanisms to promote individualised budgets should be established and pathways to relevant services such as planning, housing, employment and health should be made accessible.
- Pressure to redevelop or build new institutions as 'temporary expedients' should be resisted. Funding should only be provided for quality services that are appropriately monitored to quality standards.

On costings, we note:

- 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. There is evidence that the cost of supporting

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<sup>1</sup> See in particular Mansell, J., Knapp, M., Beadle-Brown, J., & Beecham, J. (2007). *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report.* Canterbury: Tizard Centre, University of Kent

those with greater level of need is higher than those who are more independent, wherever these residents live.

- The relationship between level of ability and cost is robust in the literature whereby greater costs are associated with those with greater levels of need.
- A finding consistent in U.S. research reviewed and UK research was that quality outcomes regarding community participation were greater for those in community-based settings.

NDA is pleased to submit this document to the Health Service Executive Working Group on Congregate Settings in order to inform their current deliberations in this field.

# MOVING TO COMMUNITY LIVING

## 1 Introduction

The provision of residential services to people with intellectual disabilities in Ireland is following international trends towards greater individualised supports and community inclusion. The Annual Report of the National Intellectual Disability Database Committee 2007, for example, observes significant increases in community-based residential provision over the last decade. The process of moving those in institutionalised care to community-based supports is promoted internationally by the European Committee of Experts on Community Living (Deinstitutionalisation) of Children with Disabilities and nationally by initiatives such as the HSE-funded Adult Day Services Review Group and the HSE Working Group on Congregate Settings for Persons with Disabilities.

Recognising the need for an evidence-based approach to guide the move towards community-based residential provision for people with disabilities in Ireland, NDA commissioned research in 2005 to examine the quality outcomes associated with accommodation services for people with disabilities. The report "Supported Accommodation Services for People with Intellectual Disabilities: A review of models and instruments used to measure quality of life in various settings", notes that over the period of the review *"relatively few studies have investigated the relationships between the costs of different forms of supported accommodation for people with intellectual disabilities"* (p.48). In fact, only one such study has been carried out in Ireland. This study, an unpublished report, was commissioned by the Department of Health & Children and was undertaken by the Centre for Disability Studies, University College Dublin in 1999. No published data therefore currently exists on the relative cost and associated quality outcomes of residential supports for people with disabilities in Ireland.

While the evidence base from academic sources on the costs of residential supports is scarce, evidence from non-academic sources has recently become available. Key publications include the recently published *'Deinstitutionalisation and Community Living Outcomes and Costs Study'*, a study examining the process and cost implications of deinstitutionalisation in 28 European countries and *'Unit Costs of Health and Social Care 2007'* which provides details of unit costs for services for people with disabilities in the United Kingdom.

In addition to these sources, a number of peer-reviewed articles outline cost methodologies for residential services which would now be considered the 'gold standard' in the field and would guide the collection of accurate cost data in Ireland. When examining cost data, it is useful to note a recommendation in the deinstitutionalisation report cited above, that 'it is vitally important to take account of costs and quality together' (p.43). There will also be an attempt to identify staffing levels where they are presented in these studies.

In the absence of any published data on the relative cost and associated quality outcomes of residential supports in Ireland, this document outlines the evidence base on:

- the process and cost of deinstitutionalisation throughout Europe
- the typical methods used to determine costs, and their impact on quality outcomes for residents, when comparing different forms of residential provision for people with disabilities
- the relative and/or actual costs, including staffing ratios, for different forms of residential provision where available (most typically in the UK)
- recommendations to NDA outlining how residential cost and associated quality outcome data could be validly gathered in Ireland if required

A number of site visits have been scheduled to inform this work. To date two visits to Wales and England were undertaken in June and July 2008 respectively. A further trip to four states in the US took place in October 2008, but is not reported on in this document.

## **2 The process and cost of deinstitutionalisation throughout Europe**

Mansell *et al.*, (2007)<sup>2</sup> have recently completed an extensive examination of the process and cost of deinstitutionalisation across 28 countries in Europe. The study was funded through the Community Action Programme adopted in 2003 and provides data on:

- (1) the number of persons with disabilities resident in large institutions throughout Europe (as defined by the European Commission as residences having 30 or more residents of whom at least 80% have a disability)
- (2) the cost comparison between institutionalised and community-based residential provision
- (3) the transition costs from institutional care to community and independent living.

A brief review of these findings is presented below.

### **2.1 (1) The number of persons with disabilities resident in large institutions throughout Europe**

In general, Mansell *et al.*, (2007) note that comprehensive data regarding the number of persons with disabilities is difficult to obtain throughout Europe. Firstly, most countries do not have a single point of contact where data on disability can be accessed. Secondly, definitions used to classify disability vary within and between countries. Despite such challenges, data on the number of residential places for persons with disabilities was sought in 28 countries throughout Europe.

The populations typically availing of residential services throughout Europe include those with physical and sensory disabilities, mental health difficulties and intellectual disabilities. Residential services can be classified according to six main types throughout Europe:

- 1) group homes where typically 5-6 persons with disabilities reside with a range of staff support from drop-in to 24 hour staffing
- 2) residential homes for 10-30 persons which are fully staffed and usually provide nursing care
- 3) campus residences where multiple dwellings are clustered on one site with shared facilities and 24 hour staffing
- 4) residential schools which provide fully staffed supports to a minimum of 10 to over 100 students in residence
- 5) social care homes or residential institutions which provide fully staffed residential supports to over 30 residents of possibly mixed disabilities
- 6) hospitals or nursing homes which provide supports to 30 or more residents in a fully staffed medical environment. Mansell *et al's* (2007) review of these services throughout Europe revealed that, in many countries, state funding is used to directly support settings for more than 30 residents while non-government organisations tend to be the main provider of smaller residential settings

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<sup>2</sup> The full report is available in electronic format at [http://www.kent.ac.uk/tizard/staff/jim\\_mansell.html](http://www.kent.ac.uk/tizard/staff/jim_mansell.html)

Of the 28 countries examined, Ireland was identified as one of the few European countries where disability registers<sup>3</sup> are used to compile information on people with disabilities. At the time of publication of the Mansell *et al.*, (2007) report, Irish data showed a total of 9,369 individuals with disabilities availing of residential support services nationwide, of which 8,228 were adults, 317 were children and 824 were of unknown age. 4,179 were male, 3,874 were female and 1,316 were gender unspecified. Most individuals (n=8,073) were identified as having an intellectual disability, some (n=515) were reported as having a physical and sensory disability, and some (n=781) were classified as having an unspecified disability.

Regarding the type of residential provision available in Ireland, the Irish disability databases identified 23 different types of residential service provision. Noting that information is not recorded on the databases regarding the size of residential facilities, that is, the number of co-residents living in each facility, Mansell *et al.*, (2007) estimated that of the 23 types of residential service provision reported in Ireland, a total of 14 had the potential to provide supports to 30 or more residents, thereby meeting the criterion for 'institutional' settings as defined in the study. Using calculations based on extrapolations from the 'typical' number of co-residents in Irish settings, the authors concluded that an estimated 5,123 individuals in Ireland may live in settings with 30 or more co-residents. This figure can be extrapolated to a prevalence estimate of 122 persons per 100,000 population residing in institutionalised care settings nationwide.

The Irish prevalence estimate can be contextualised by noting that, using the same methodology as outlined above, the UK reported a prevalence estimate of 110 per 100,000 population. Sweden, having completed the deinstitutionalisation process, reported a zero estimate. Eastern European countries dominated the upper end of the prevalence range with estimates of 539, 535 and 439 per 100,000 population being reported for Estonia, Latvia and Lithuania respectively. Using these prevalence estimates, which are devised from the 'typical' number of co-residents in each country, a total of 1,039,562 individuals with disabilities are estimated to reside in institutionalised settings throughout Europe (Mansell *et al.*, 2007, Table 10, p.32).

## 2.2 The Economic Framework

Throughout Europe, institutionalised care has dominated the provision of supports for persons with severe and chronic disabilities. Congregated settings were the first choice of service providers who believe that concentrating skilled professionals in one location provided optimal supports for residents. In addition, segregated settings were the preferred choice for some families who were unable or unwilling to provide supports to their relative. Undoubtedly, the economies of scale which accrue to large congregated settings provided a financial incentive to communal provision. The economies of scale argument is that the per person cost of providing services to residents decreases as the number of residents increases. This argument, while economically compelling, fails to factor the quality of service into the equation. As Mansell and colleagues note '*the archetypal institution is cheap to run*' if care is replaced by containment (p.43).

In determining a successful pathway from institutionalised settings to community-based supports Mansell *et al.*, (2007) recommend that decision makers take due cognisance of variation within and between European countries regarding the current structure of service provision, the underlying financial arrangements of these services and the mechanisms through which they are funded. Patterns of service provision, for example, differ markedly throughout Europe. The role of informal care givers, (e.g. family) and formal supports (e.g. housing authorities, health care providers) may be influenced at a micro level by a person's level of ability and at a macro level by the structure of these supports nationally. Of critical importance is the coordination of these supports most especially for persons with multiple and complex

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<sup>3</sup> National Intellectual Disability Database & National Physical and Sensory Disability Database can be accessed at [www.hrb.ie](http://www.hrb.ie)

needs. Mansell and colleagues caution that the coordination of these supports is a fundamental requirement of community-based service provision. While the provision of services to people with disabilities was traditionally led by state agencies throughout Europe, more recent and wide-ranging service provision may now combine public, voluntary and private sectors. The different funding mechanisms, eligibility criteria and organisational ethos of these organisations must be appropriately coordinated if a seamless provision of services across disciplines such as health, housing and social care, is to be realised. Policy makers must consider the implication of multiple support providers when commissioning and coordinating services.

Throughout Europe different arrangements are employed to finance the provision of supports for persons with disabilities. Mansell and colleagues identify four key financing arrangements for health and social care services (1) out of pocket payments by service users or family, also termed 'user charges' (2) voluntary insurance, also termed 'private insurance' (3) tax based support funded by national, regional or local taxes on the basis of need and (4) social insurance funded via employment contributions and also provided on the basis of need. More recently, self-directed options are beginning to emerge as a preferred option providing people with disabilities an opportunity to gain control over their own financing arrangements by purchase individual supports of their choosing. Again, policy makers considering a deinstitutionalisation programme must take due cognisance of mechanisms by which existing and proposed services will be financed.

'Funding routes' refer to the methods by which sources of funding raised from financing arrangements reach service providers. One such route is 'central funding', whereby providers receive central funding, most likely performance related, to provide a particular service (e.g. state sector hospital). Another typical funding route is commissioning, whereby centrally raised revenue is awarded to service providers from commissioners following a contractual agreement to provide a given service. Commissioning can become complex when joint commissioning is required, for example across housing, social and health services. Finally, self-directed options are the most recently developed service option and permit people with disabilities to negotiate and commission individually based services.

Clearly, any country in Europe embarking on a deinstitutionalisation programme will need to identify and consider the implications of differing patterns of service provision, varying financial arrangements and variable funding routes on the transfer of people from institutional care to community-based living. Citing the experiences of developing community-based service provision in England, Italy and Germany as examples throughout Europe, Mansell and colleagues, as outlined below, identify key barriers and facilitators to the move towards community living.

### **2.3 Policy Frameworks and local plans**

Mansell *et al.*, (2007) note that at the most fundamental level, a policy framework is required to direct a move towards community based residential provision. International frameworks provide a context for national policy making; these include the 1948 *Universal Declaration of Human Rights* and more recently, the 2006 *UN Convention on the Rights of Persons with Disabilities*. Article 19 of the UN Convention, for example, provides for 'the equal right of all persons with disabilities to live in the community'. Mansell *et al.*, (2007) note that compliance with these declarations is variable throughout Europe. Practices such as 'cage beds', solitary confinement and electro-convulsive therapy without anaesthetic occur in many institutionalised facilities across Europe, in direct contravention of international agreements. Policies at national level undoubtedly lend greater weight to the implementation of best practice. *Valuing People* (Department of Health, 2001), the UK's policy document on intellectual disability services, for example, acknowledges the poorer quality of life experienced by those in hospital based settings and makes a commitment to enable all people with intellectual disabilities the opportunity to express greater choice and control over where and how they live.



In addition to a national commitment to deinstitutionalisation, Mansell and colleagues advocate local planning to ensure a smooth transition from congregate to community settings. These locally based plans should include realistic timetables for transferring residents, transferring funding systems (typically out of the health system), redeploying staff, developing community supports, realising capital from congregate sites, consultation with stakeholders and most importantly, plans to inform and consult residents about any proposed transfer. Above all, plans should be flexible and allow for adaptation as findings emerge. The closure of Darenth Park in the UK, for example, originally included plans to build smaller congregated settings. These plans were reviewed in light of the successful integration of residents in ordinary housing, an option deemed more preferable than congregated settings.

Consultation with stakeholders is identified by Mansell and colleagues as a necessary condition for the successful transfer of services to the community. Preferences of residents, family, staff and the wider community all require due consideration. Concerns from all quarters have resulted in 'trans-institutionalisation' where residents are moved to settings such as village campuses or secure units, which although on a smaller scale to the institutionalised settings residents hailed from, are typically segregated with few opportunities for community integration. Failure to appropriately address the concerns expressed by stakeholders can thus act as a major barrier to community living for people with disabilities.

A lack of appropriate supports within the local community is also identified by Mansell *et al.*, (2007) as a barrier to community integration. These supports may take the form of skilled staff, or more typically, rely on informal care from family and friends. The social and economic burden of informal support can be vast. Care giver burden can result in psychological stress and poor health status while limitations in accessing full time employment due to the caring role can impact on families' financial circumstances (Emerson *et al.*, 2004; Harrison *et al.*, 2004). Of concern is a reduction in the potential pool of such carers. Changes to the traditional family structures, large geographical distances between family members and the growing numbers of women working in full time employment, all contribute to a reduction in the availability of informal carers. Financial incentives and flexible employment options are required across Europe to ensure that the level of informal caregiving is appropriate to meet the needs of those requiring this support. As Mansell and colleagues note "*the cost of the alternative – staffed care in residential settings or intensive models of home care – is too high to contemplate*"(p.77).

In the absence of informal family support, skilled staff are required to support residents in the community. These staff may include those who formally worked in institutionalised settings and who subsequently transfer to community residences. Investment is required to ensure that institutional practices do not transfer to the new settings. Mansell *et al.*, (2007) acknowledge that attracting new staff can prove problematic as salaries for support staff are typically low throughout Europe resulting in low levels of recruitment and high staff turnover<sup>4</sup>.

It is important to recognise that the closure of a large scale residential facility impacts considerably on the local economy. It is unlikely, for example, that all residents will be re-housed within the local community. Some residents are likely to return to their place of origin. The level of staffing required to support local community services is therefore likely to be lower than that required previously in the institutional facility. Local staff who cannot be redeployed may now face redundancy and or early retirement options. Strategic planning, such as the location of new community based residences, can assist in reducing the impact of the closure on the local economy.

In summary, the transfer of people with disabilities from institutionalised care to community-based living is promoted by international conventions. A commitment by Governments throughout Europe to support a policy of deinstitutionalisation promotes compliance to these

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<sup>4</sup> It should be noted that recent site visits to the UK by NDA revealed that Irish support staff receive considerably higher salaries than their counterparts in the United Kingdom.

conventions and provides a framework for the closure of institutional facilities. In addition, regional and local planning is necessary to ensure the successful transfer of residents to community living and to provide optimal supports to local communities where institutions were previously located.

## **2.4 (2) Examination of cost comparisons between institutionalised and community based residential provision**

Mansell and colleagues identify four costs which should be considered when undertaking an examination of the costs of residential provision for people with disabilities. Firstly, there is the direct cost incurred by the lead agency providing support to the person with a disability. Secondly, indirect costs are likely to be incurred where additional services are provided by agencies other than the lead agency. Thirdly, hidden costs are incurred where support is provided by unpaid carers. These costs include, for example, the loss of income caregivers may sustain when they are unable to secure or maintain employment because of their caregiving role. Finally, there are intangible costs which are realised from the 'burden of caregiving'. Intangible costs may be manifest in reduced health related quality of life and other stress related illnesses. While some of these costs are more easily identifiable when examining costs and quality outcomes, all are important components of the quality cost equation.

Mindful of the visibility of different sources of costs, Mansell *et al.*, (2007) review a selection of the cost and quality evidence base for institutionalised and community-based residential supports. The research is largely UK based and comprises mostly evaluations of deinstitutionalisation projects undertaken for residents with mental health difficulties and for residents with intellectual disabilities. A small number of studies have examined similar projects evaluating the transfer of residents with physical and sensory disabilities but, given the small evidence base, these will not be reviewed in this report. Key questions posed in the review are whether the cost of care in the community today is less than the cost of institutionalised care, whether the cost of care is higher for those with greater levels of needs, whether community care is less expensive following adjustment for level of need, and if not, whether the additional cost results in better quality outcomes for residents.

UK studies comparing the cost of mental health provision in congregate hospitalised settings with the cost of provision in community care settings (Knapp *et al.*, 1997, Chisholm *et al.*, 1997) reveal that community care is significantly less expensive. Studies in Germany (Hafner & van der Heiden, 1989) also report community care as less expensive than hospital care but note a sharp increase in costs with level of need, leading the authors to comment 'it would be appropriate for these patients to remain in hospital' (p.16). UK studies have replicated these findings (Knapp *et al.*, 1995) indicating that for those with less severe mental health difficulties, community care is more cost effective than hospitalised care but that the cost of community care exceeds that of hospitalised care for those with more severe mental health difficulties. The authors note that the increase in investment for those with greater levels of need is reflected in improved quality outcomes for these residents. In commenting on these findings, Mansell *et al.*, (2007) state that the higher costs required to provide community-based accommodation for those with more severe mental health difficulties should not be a deterrent to their move to community-based settings, but rather should offset against gains in quality of life. Furthermore, the successful development of community-based options for those with severe and multiple intellectual disabilities illustrates how those with complex needs have been ably supported to experience quality outcomes in community settings.

Longitudinal studies conducted in the UK provide valuable information on the trajectory of cost and quality outcomes of community-based provision for those with mental health difficulties over time. One of the most comprehensive evaluations of mental health hospital closures in the UK was conducted over a 12 year period under the auspices of the UK Care in the Community programme (Beecham *et al.*, 2004). The weekly cost of community care was less expensive than costs in hospital but the range was wider reflecting the variation in use of

community facilities. While community integration was limited over the intervening twelve years, residents in community-based accommodation expressed a preference for living in the community and had no wish to return to hospital care. The study replicated previous findings indicating that over time, there is no cost differential between hospital and community-based supports, but there is a 'cost-effective' advantage of greater quality outcomes for those residing in the community.

Mansell and colleagues also reviewed quality and outcome studies examining community-based supports for people with intellectual disabilities. Again, the key issues were whether quality and outcomes were more favourable in community-based settings, whether level of need mediated in this relationship, and if costs were identified as being higher in community settings, whether these higher costs were associated with greater quality outcomes.

Mansell *et al.*, (2007) review an extensive study examining the quality and costs of different types of residential provision for people with intellectual disabilities undertaken in the UK and Ireland by Professor Eric Emerson and colleagues in the late 1990s. Comparisons of NHS residential centres, village communities and dispersed community housing revealed that, after adjusting for residents' level of ability, village communities were the least expensive option but provided marginally lower quality outcomes when compared with dispersed housing<sup>5</sup>. Both village communities and dispersed housing were however associated with specific benefits for residents. This comprehensive study has guided UK policy on residential options for people with intellectual disabilities most specifically through the acknowledgement by UK Government that NHS Residential Campus settings produce significantly poorer outcomes for residents than village communities or dispersed housing options (Valuing People, Department of Health, 2001, p.71).

In a comparison of community-based living options for people with intellectual disabilities Felce *et al.*, (2008) provide evidence that, after controlling for level of ability of residents, the cost of care for those residing in fully staffed settings was almost three times higher than for those supported in semi-independent living. Semi-independent living was defined as having no paid staff support for at least 28 hours per week when residents were awake at home. The authors acknowledge that semi-independent living provides greater benefits for residents, but also note the slightly lower level of health checking and problems with money management experienced by these residents. The authors state 'outcome differences where fully staffed group homes might be judged superior to semi-independent living may also be viewed as underpinned by level of independence: slightly lower health surveillance, greater money management problems and opportunities for an unhealthy lifestyle might be associated with greater self-determination' (p.98).

The twelve year follow up of the Care in the Community demonstration programme cited above (Beecham *et al.*, 2004) followed 400 people with intellectual disabilities who moved from hospital to a variety of community-based settings. The study revealed that the cost differential between hospital and community provision varied over time (Hallam *et al.*, 2006) as although the cost of community provision exceeded that of hospital based care one year following deinstitutionalisation, no differences were found in costs twelve years later. After controlling for residents' level of ability, costs in minimal support settings were significantly lower than in residential and nursing homes while costs in group homes were significantly higher. The authors conclude that quality of life improvements were achieved for those in more independent settings without costs exceeding those previously incurred in hospital settings.

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<sup>5</sup> The specific outcomes are not cited by Mansell *et al.*, (2007). Reference to the original study cited (Emerson *et al.*, 1999a) identify benefits of dispersed housing when compared with village communities in relation to size and homeliness of setting; not living in a house which also provides short-term care; ratios and qualifications of senior staff; access to independent advocacy; a less institutional social climate; social integration; and access to leisure/recreational activities. In contrast, village community settings were identified as offering particular benefits in the areas of internal planning procedures; access to routine health care and day activities and selected aspects of safety/risk.

Research examining the relationship between level of need of residents with intellectual disabilities and costs has consistently reported greater costs for those with higher dependency needs, in particular those with challenging behaviour. Mansell and colleagues acknowledge that this relationship is complex and is mediated both by the sector (whether public or private) and size (economies of scale) of the residential setting. That is, larger NHS facilities have greater options to disperse the responsibility for supporting those with greater needs across the staff complement. As such costs per resident are lower for each additional resident. In contrast, private or voluntary facilities are more likely to face an increase in costs for each additional resident (Knapp *et al.*, 2005). Mansell *et al.*, (2007) conclude however that although there are wide variations in costs associated with persons with varying levels of intellectual disability, much of the between individual variation in cost remains unexplained.

On the basis of the literature reviewed, Mansell and colleagues make the following observations regarding the relationship between costs and quality outcomes. "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" (p.97). There is evidence that the cost of supporting those with greater level of need is higher than those who are more independent, wherever these residents live. Finally, a new model of support could be more expensive than the model it replaces, but may be more 'cost-effective' by offering better quality outcomes to residents. Decision makers, in collaboration with persons with disabilities, will need to consider which quality outcomes they prioritise (e.g. employment, social integration) within a new model of care.

## **2.5 (3) Identify transition costs from institutional care to community and independent living**

While the findings reported above examine the relationship between cost and quality outcomes pre and post community living, they do not address the relationship between these variables during transition. In particular, the impact on costs as institutional settings close and community-based services become established must be recognised and appropriately resourced by service planners.

Mansell and colleagues estimate that based on the evidence of costing mental health care provision conducted by Knapp *et al.*, (1997) the cost of care provision in the community for a person moving from institutional care will be lower than the current costs of the person in institutional care, but will be higher than the current cost of those who already reside in community care. These findings reflect the fact that the population of persons residing in the community are typically more independent than those residing in the institution. As the process of deinstitutionalisation commences, those residents who are more able are most typically the first to be offered a transfer to community living. In time, only those with greater levels of need remain in the institution at which point they are considered for a transfer to community living. The implication of this pattern of transfer for costs is that the 'average' cost per resident in both institutionalised and community-based settings increases.

An awareness of the implication for costs as persons of different levels of ability move to community-based settings is important for decision makers. By costing community residential places solely on the basis of an 'average' cost of those current living in the community, typically those with higher levels of ability, projections for the cost of community-based provision for those with greater levels of need are likely to be under-estimated. Decision makers also need to take cognisance of the staffing requirements in the institutional setting that are necessary to the point of closure. Typically, both the most able residents and the more dynamic staff are first to move to the community. The institutional setting can therefore be left with poor quality staffing and residents with complex needs. These challenges reinforce the need for long term and informed planning of institutional closures.

Clearly, the closure of an institutional setting will realise some financial value once the property and any adjoining land is sold. The income realised from such a sale will vary depending on the location of the institution and the potential alternative use for the property. Settings in prime locations which have options for redevelopment will realise greater income than institutions in remote and potentially undesirable areas. No income however is likely to be realised until the institution is closed. Prior to this closure, new community based residences are required to be sourced, purchased and converted where necessary to meet the needs of residents. As a consequence 'double' costs emerge for maintaining the institution to an acceptable standard until the last resident has left, while simultaneously funding the newly established community based residences. These 'hump' costs require careful planning to ensure quality services are delivered to residents. Mansell *et al.*, (2007) caution that hump costs are always required and that any 'cost neutral' proposals are likely to result in substandard settings with inadequate supports.

When planning the closure of an institution, one option is to ring-fence the budget previously awarded to the institution for community services. This transfer of budgets avoids 'leakage' of the budget to other services outside the disability field. 'Dowries' have been used in the UK by local health authorities whereby residents were moved to the community with a protected budget for their service provision. Alternatively, integrative funding structures can exist where the budget previously used to support individuals in institutionalised care is not ring-fenced but rather integrated into the mainstream health and social care budget. This integrative approach has the advantage of being administratively simpler than ring-fencing and provides greater opportunities for those employed within the disabilities sector to liaise with colleagues working in mainstream services. Mansell and colleagues acknowledge that different health and social systems will favour separate or integrative funding streams. The issue is which option, within local structures, is most likely to incentivise good working relationships across community services and thereby provide optimal supports to those moving to the community.

Mansell *et al.*, (2007) note that budgets may also be held at different levels within a state, whether national, regional, local or individual. Hospitals, for example, may receive a lump sum budget by central government or they may receive funding from a local authority. Devolution of funding may extend to local teams or professionals such as care managers. This individual level funding should theoretically allow for a more needs led service whereby those who are familiar with the individual and the local community are free to purchase appropriate supports. Devolution at this level however may result in more conservative options for people with disabilities as there is less of a financial cushion in the event of a poor decision. Similarly, strategic decisions at national or regional level are more challenging when budgets are devolved to local level.

A more recent development throughout Europe is the option of self-directed care. While variously defined, self-directed care provides opportunities for individuals to exercise choice over the types of services received. Processes such as person-centred planning and direct payments empower individuals to select services across a variety of domains such as health, social care and housing. While direct payment options are undeniably attractive from a rights-based perspective, they require vigilance. Individuals and their advocates shoulder much of the responsibility of securing and maintaining support. The risk of exploitation where funding is transferred to a vulnerable individual is a cause for concern if not appropriately considered.

The transfer from institutional to community living requires the coordination of multiple services such as housing, income support, health, social care, and education all of which may have been previously managed under the auspices of the institution. For residents who previously had their needs met through one system, typically that of health, a move to community living is a move towards a more fragmented system whereby needs are met from a variety of sources that are resourced from different funding streams. The successful coordination of these funding streams is required for a seamless service provision. Fragmented service provision was a feature of all three countries, England, Germany and Italy, case studied by Mansell and

colleagues. A variety of mechanisms have been implemented to streamline the coordination of multiple service providers including the establishment of 'care brokers', the designation of one service provider as 'lead agency', and the use of self-directed care budgets. Local authority care managers, the typical commissioner of services in the UK, may assist in the coordination of these services. The care managers typically cover the full range of responsibility for service provision from initial case finding, through assessment, planning, monitoring and culminating in case closure.

To conclude, the transition period while institutionalised facilities close and community-based settings emerge requires careful planning. Typical patterns of migration to community living are evident and have implications for determining costs. Service planners will need to consider hump costs which will be required to support both institutional and community settings during transfer. Service planners will also need to consider the escalating costs associated with moving those with greater levels of need to the community. Given these established patterns, Mansell *et al.*, (2007) call for long term localised planning, including accurate and realistic needs assessment of the entire institutionalised population.

## **2.6 Recommendations**

Mansell *et al.*, (2007) conclude with a series of recommendations, the more salient of which are briefly reviewed:

- The role of Government at national and regional level is central to providing a vision for change. A comprehensive vision for community options can incorporate incentives for change and promote positive demonstrations of good practice. Legislative support for inclusive practices should be encouraged.
- Stop building new institutions and spend the majority of available funds to develop services in the community
- Institutional settings should be required to permit site visits and encouraged to promote community services. Inspections to evaluate living conditions and quality of life should be undertaken. The results from inspection visits should be open to public scrutiny and redress.
- Innovative services, such as support living, should be promoted as models of best practice and evaluated for quality and cost. Residents of all levels of ability should be encouraged to participate in new service developments.
- Mechanisms to promote individualised budgets should be established and pathways to relevant services such as planning, housing, employment and health should be made accessible.
- Pressure to redevelop or build new institutions as 'temporary expedients' should be resisted. Funding should only be provided for quality services that are appropriately monitored to quality standards.

### **3 The typical methods used to determine costs, and their impact on quality outcomes for residents, when comparing different forms of residential provision for people with disabilities**

An extensive review of the literature regarding quality outcomes in residential settings was commissioned by NDA in 2005. The report "*Supported Accommodation Services for People with Intellectual Disabilities*" (National Disability Authority, 2007) reviews models and instruments used to measure quality of life in residential settings. The report includes a comprehensive systematic review of 67 deinstitutionalisation peer reviewed articles and examines the relationship between variations in quality of life domains (independence, civic participation and wellbeing) and residential options for people with disabilities.

This current report aims to compliment the 2007 report by focusing on the evidence base specifically in relation to the cost of various residential models. The scope of this research did not permit a full systematic search of papers and as such this review does not claim to be exhaustive. Rather, the aim of this review is to present some of the typical methodologies cited in the literature for estimating residential costs and to present some of the key findings from studies estimating the relationship between quality outcomes and costs of different models of residential provision for people with disabilities. The review was guided by two objectives; to review the methodologies by which the costs of residential services are determined in peer reviewed studies and to review the actual costs, and associated staffing ratios where available, as presented in these publications.

### **4 Review of methodologies by which the costs of residential services are determined in peer reviewed studies comparing the costs of different residential provision**

One methodology clearly dominates the UK costing literature. In the present review, numerous peer reviewed publications were identified employing variations of this methodology. These studies included longitudinal investigations of the impact of residents' transfer from hospital-based to community-based settings (Beecham *et al.*, 1997; Myles *et al.*, 2000; Cambridge *et al.*, 2002; Hallam *et al.*, 2006) and cross-sectional studies examining quality outcomes and costs among a range of hospital and community-based residential options (Felce *et al.*, 1998; Emerson *et al.*, 2000a; Emerson *et al.*, 2000b, Emerson *et al.*, 2001; Hallam *et al.*, 2002; Robertson *et al.*, 2004; Knapp *et al.*, 2004; Felce *et al.*, 2008).

This costing methodology derives from the work of Beecham & Knapp (1992) and Knapp (1995). Long-run marginal opportunity costs of accommodation are determined by calculating the revenue costs from four sources: (1) direct staffing costs within the resident's home (ii) non-staffing costs within the resident's home including lighting, heating, provisions, etc., (iii) staff costs across the entire residential site and (iv) central overheads borne by the agency (calculated from the agency's accounts where possible or by adding 5% to revenue costs if not available). Capital costs (buildings and equipment) are based on valuations, council tax bands or rental costs. All capital costs are annuitised over an expected 60 year life span at a discounted rate of eight percent. Where organisations cannot estimate the cost of replacement for furnishings or fittings, ten percent of the annual building cost is used.

Typically these costs are gathered using a pro-forma questionnaire in conjunction with income and expenditure accounts for each facility where individuals reside and from the staff-completed Client Service Receipt Inventory survey (CSRI; Knapp, 1995). The CSRI collects information on each resident's use of services over the preceding three months, any income held by the resident, any contribution made to residential costs and the particular staffing levels within the residence. Staffing levels are typically averaged per resident unless additional information is available regarding the possible weighting of these costs for residents who may require additional staffing input to meet their needs. For hospital and other community-based services not provided by the organisation, unit cost estimates are employed. These unit costs are derived annually by the Personal Social Services Research Unit (PSSRU) and will be discussed further below.

Finally, some individuals will be in receipt of payment for work-related activities, whether in sheltered or other supported forms of employment. These costs are typically awarded a zero cost on the basis that the individual's earnings are offset by the cost associated with supervisory staff required to support the individual in the work-related activity.

Accommodation and non-accommodation costs are thus calculated and then totalled to produce an individual care package cost per resident. Numerous studies conducted in the UK have utilised this costing methodology to make either longitudinal or cross-sectional comparisons between various models of residential provision.

The unit costs referred to previously are published on an annual basis by the Personal Social Services Research Unit (PSSRU) at the University of Kent. These annual publications, which commenced in 1994, aim to collate routinely collected data and information to produce national unit costs for health and social services. Both top-down and bottom-up approaches are utilised to determine these costs. Top-down estimates divide the total expenditure for a given service by the number of units produced or delivered over a given time period, typically one year. Bottom-up approaches are the preferred choice in determining unit costs. These estimates are derived from a separate determination of the costs of each element of the service (e.g. buildings, staffing levels) which are then computed together to produce an overall cost. This latter approach requires a thorough understanding of the various components of a given service. The Unit Cost publication for 2007 provides costing estimates for a range of health and social care services including services for older people, people with mental health problems, people with intellectual disabilities, children and families, people with substance misuse problems and people with physical and sensory disabilities (Curtis, 2007). Unit costs are also provided for community-based health and social care staff including nurses, general practitioners, social workers etc. The full publication is available for review at <http://www.pssru.ac.uk/>

By way of example, unit costs for intellectual disability services will be briefly outlined. Unit costs are determined for six types of service provision for this population

- (i) group homes,
- (ii) village communities,
- (iii) NHS residential campus settings
- (iv) supported living schemes,
- (v) local authority day care
- (vi) voluntary sector respite services.

The four residential costs outlined in (i) to (iv) above are all based on the work of Emerson and colleagues who collected quality outcomes and costing data on behalf of n=500 people with intellectual disabilities availing of these types of residential supports. Recall that Emerson and colleagues employed the Beecham & Knapp (1992) costings methodology outlined above. The unit cost data for these services is therefore based on detailed costing data gathered on behalf of each individual resident who participated in a large quality and costs study. Total costs per



service are presented across a number of costs including capital costs, revenue costs, overheads, external services, and personal finance. A multiplier for level of ability is also provided where relevant. The global costs for the four residential models in the 2007 publication are presented as a weekly cost of £1,306 for NHS residential campus provision, £1,228 for supported living schemes, £1,075 for group homes and £796 for village communities. The authors note, however, that the unit costs need to be used with some caution on the basis that actual costs may vary from estimated costs.

The above costings methodology is clearly the preferred option for determining costs in the UK literature. Other methodologies are identified in the literature, a number of which rely on drawing down expenditure data from the funding or commissioning body. These studies are typically non-UK based. Howe *et al.*, (1998), for example, obtained financial data from the Oregon Office of Developmental Disability Services to compare the quality of service provision in supported living and traditional residential options. Similarly Spreat *et al.*, (2005) accessed the Oklahoma State paid claims database for ICF/MR (Intermediate Care Facilities for People with Mental Retardation) and Waiver funded schemes in order to compare costs of community-based and congregate care settings. Rhoades & Altman (2001) obtained financial data from the Institutional Population Component of the National Medical Expenditure Survey (1987) sponsored by the Agency for Healthcare Research and Quality (AHCQ). This database provided nationally representative data on behalf of residents with intellectual disabilities in settings with three or more residents. The costing methodologies outlined in these studies typically reflect the 'top down' option identified by Curtis (2007). Recall the 'bottom up' process pioneered by Beecham & Knapp (1992) apportioned the specific aspects of service utilised by a resident into an individualised cost estimate for each resident. Stancliffe & Keane (2000), in an Australian study comparing matched samples of residents in group homes and semi-independent living, illustrate this 'bottom up' methodology by apportioning staff costs for individual consumers. Interestingly, cost data in this study excluded capital costs and non-resident services provided independently of accommodation (e.g. day services, employment and health care).

This brief review of a selection of costings studies published over the last decade reveals a strong relationship between costing methodology and the country of origin where the research was undertaken. Studies conducted in the UK are typically reliant on a bottom-up methodology where individual variation in service use is apportioned into a total cost per resident. The validity of this costing methodology is reflected in the fact that they are used in the calculation of national unit cost estimates for health and social care services. It is interesting to note that this methodology has in fact been previously applied within Irish settings (Walsh *et al.*, 2000) on behalf of n=125 residents of village campus and group home settings. This data was however collected almost a decade ago, and unfortunately is in Irish punts, the currency preceding the euro. Given the changes in the Irish economy and investment in the health sector over the last decade it is likely that these data no longer adequately reflect the real cost of these services (Nolan *et al.*, 2007).

## **5 Actual Costs, and Associated Staffing Ratios where available, as presented in Peer-Reviewed Studies comparing the costs of different residential provision**

This section reviews a selection of studies published in the previous decade that provide details of actual costs of services, and staffing ratios where available, across a range of residential options for people with disabilities. For ease of comparison the studies are presented under three categories; (1) UK longitudinal studies using the Beecham & Knapp (1992) and Knapp (1995) methodology; (2) UK cross-sectional studies using the same methodology; (3) Non-UK studies using a variety of methodologies.

## 5.1 1. UK Longitudinal Studies using Beecham & Knapp Methodology

Beecham *et al.*, (1997) compared the average weekly cost of n=192 residents one year following resettlement from hospital-based settings to four models of community-based residential supports in Northern Ireland: residences provided by statutory bodies; residences provided by voluntary non-for-profit organisations; privately owned residential and nursing homes; and independent living arrangements (including living alone or with family or friends in domestic accommodation). The study found that the total package of care (all costs were 1994/1995) was most costly in statutory facilities (weekly average cost = £517.36). Voluntary organisations, including housing associations were found to have similar total costs of care to private nursing/registered care homes (weekly average cost £351.26 versus £323.33 respectively). Finally, the total cost of independent living, at a weekly average of £133.63, was the least costly of the four residential models. It is important to note that these costs are not adjusted for resident characteristics.

Cost comparisons were also made between the average hospital inpatient cost at the hospital of discharge and each resident's current average community care cost. The average hospital cost (£573.94) exceeded the current average community care cost (£355.57) across all hospital sites from which discharges were made. The full range of care costs across all community residences ranged £106.18 to £816.15 illustrating that some community-based care packages exceed the cost of former hospital based care. The reliance on 'average' costs is noted by the authors who identify a six fold range in costs between the minimum and maximum cost per resident. This wide variation in costs is typically observed in most residential costing studies.

Myles *et al.*, (2000) conducted an extensive evaluation of a resettlement programme for residents of Gogarburn and Tornaveen, two large residential hospitals located in Scotland. A total of n=76 residents participated in this longitudinal study which was conducted six to nine months following their consecutive discharge from the hospitals. Residents were transferred to new accommodation in eighteen community-based homes ranging in size from single person flats to group homes for 36 or more residents.

The community-based per resident costs were examined by level of ability, age and type of residence. Costs were found to be higher for those with greater levels of need and to decrease with age. The relationship between level of ability and cost is robust in the literature whereby greater costs are associated with those with greater levels of need. The relationship between age and cost identified in the present study is thought to reflect the lower accommodation costs of residential settings for older persons. Total costs differed by residential type whereby higher costs were observed in residences with lower number of co-residents. The average annual costs for single person flats (£55,328) exceeded that of a 3-5 resident accommodation (£53,506) which in turn exceeded that of a 6-10 resident setting (£31,699). The least expensive residential option was that providing for 36 or more residents, where average annual costs were £22,222. Clearly there is evidence of economies of scale. In a similar finding to Beecham *et al.*, (1997), costs were higher in statutory facilities when compared with voluntary or privately run facilities. Another comparative finding with the Beecham study is the variability in costs with an almost five-fold variation in costs being reported across the sample.

Myles *et al.*, (2000) thus report that greater costs are associated with more dependent residents, of younger age, who reside in smaller dwellings. The authors also note however that cost and resident outcomes were tenuously related. That is, the most expensive services did not realise proportionally greater gains in outcomes for residents.

Cambridge *et al.*, (2002), in the most comprehensive longitudinal study of deinstitutionalisation carried out in the UK entitled *Care in the Community*, examined the costs of residential provision for n=275 people with mental health and intellectual disabilities. To date, the study has twelve years longitudinal data on residents following their discharge from hospital settings. Weekly costs of the total service package were determined for residents in four different types of

community-based accommodation, and, as has been reported previously, were found to vary considerably both within and across settings.

Staffed group homes for between two and five residents were the most costly option (averaging £823 per week), followed by residential/nursing home facilities (averaging £797), hostels (e.g. six or more residents and continuous or regular staffing; averaging £610), and minimal support settings (e.g. unstaffed settings including individual units in larger complex settings; averaging £438). Similar to previous findings, NHS statutory facilities were found to be most expensive options and providers of minimum support settings the least expensive.

Overall the average weekly cost of community care twelve years on (£668) remained more expensive than hospital-based support (£643), but lower than the community based costs at nine months following discharge (£785) and five years following discharge (£761). As such there is a continuing decline in costs over time (all costs are set at 1998/1999 prices).

In general, residents reported high levels of satisfaction with the quality of their accommodation following resettlement, the most positive aspects being the living environment, the social milieu and their level of independence. Those living in supported accommodation expressed the highest level of satisfaction with their quality of life. As per previous findings (Myles *et al.*, 2000), the authors report that there was no evidence of a relationship between cost and outcomes for residents in terms of changes in skills and behavioural problems from hospital to community settings.

Hallam *et al.*, (2006) conducted further examination of the financial data gathered during the *Care in the Community* longitudinal study. While the Cambridge *et al.*, (2002) study included residents with both mental health and intellectual disabilities, the Hallam *et al.*, (2006) study is restricted to those with intellectual disabilities. The study examined cost comparisons for n=103 residents with intellectual disabilities across the same four residential models previously examined by Cambridge *et al.*, (2002). A similar pattern of costing was observed whereby, following adjustment for level of need, the cost of minimum support accommodation (average weekly cost £354) and hostel accommodation (average weekly cost £593) were significantly lower than the cost of residential/nursing homes (average weekly cost £812) and staffed group homes (average weekly cost £819). The finding that community care costs remained more costly than former hospital care, but that the disparity in cost was steadily reducing over the twelve year period, also reflects the findings of Cambridge *et al.*, (2002).

Finally, Hallam and colleagues note that while an association was reported between the cost of supports and changes in the skills and behaviours of residents one year following resettlement, no such relationship was observed at either five year or twelve year follow up. The authors describe the lack of association between costs and outcomes as 'disappointing'.

The selection of papers above demonstrate trends of longitudinal studies comparing costs of residential facilities where highly similar costing methodologies have been employed to determine costs. There is some consistency across findings. Overall, quality outcomes are typically more favourable in community-based settings when compared with hospital-based settings. Higher costs are associated with those who have greater levels of need, and, as Mansell *et al.*, (2007) note, this finding is likely to be consistent across all residential settings.

The cost of community-based provision has been reported as less expensive and more expensive than hospital-based provision. While these results may seem contradictory it is important to note that where community costs have been found to exceed hospital costs, this price differential decreases over time.

Costs were found to vary by service provider with statutory services typically being reported as more expensive than either voluntary or private residential nursing provision. With regard to the variation in costs of specific types of residential settings, models that support independent living with minimal supports were typically found to cost less.

In interpreting findings from these longitudinal studies two issues have been identified as causes for concern. Firstly, there is considerable variation in the costs both within and across residential settings. As such, results based on 'average' costs should be interpreted with caution. Secondly, there is little evidence to suggest any relationship between quality outcomes for residents and costs. While this issue is not debated at length in the studies above, it is appropriate to ask what factors, if not cost, contribute to greater quality outcomes for residents.

## **5.2 2. UK Cross-sectional Studies using Beecham & Knapp Methodology**

The studies reviewed in this section present costing data from cross-cultural studies comparing the quality and costs of samples of people in different residential settings. All studies employ the Beecham & Knapp (1992) and Knapp (1995) costing methodology.

In an examination of the costs of service provision for those with severe challenging behaviour, a group typically excluded from community-based settings, Felce *et al.*, (1998)<sup>6</sup> compared total costs for a sample of residents in hospital settings (n=17) with a sample of residents in community-based settings (n=17). Similar to previous findings, considerable variation was observed in the costs determined per resident; in fact, variation in costs for residents availing of the same model of support reported a threefold difference.

Mindful of the heterogeneous nature of these costs, the findings did reveal a clear difference in the average costs of supports to residents in hospital settings (total three month cost £11,464; range £7,580-19,329) when compared with residents in community settings (£22,898; range £12,999-35,538). The increased cost of community-based provision is apparent for both accommodation and day care services. While the community houses were found to be almost twice as costly as hospitalised care, the authors note that these increased costs should be offset against better quality outcomes observed for these residents.

With regard to staffing levels, the data indicated that staffing costs comprise a higher proportion of accommodation costs (82%) within community dwellings when compared with hospital settings (68%). In addition, further examination of the relationship between staffing ratios within community-based settings revealed that residents in settings with higher staffing ratios did not benefit from better quality outcomes when compared with residents in settings with lower staff ratios. Felce *et al.*, (2002) comment that this finding replicates previous studies demonstrating a tenuous relationship between staff input and quality outcomes (Cambridge *et al.*, 1994; Hatton *et al.*, 1996; Stancliffe & Lakin, 1998, Emerson *et al.*, 1999a, 1999b; Felce *et al.*, 2000).

Emerson *et al.*, (2000a)<sup>7</sup> present findings from an extensive study commissioned by the UK Department of Health comparing costs and quality outcomes for n=500 residents of NHS residential campus settings, village communities and dispersed housing. After adjusting for residents' level of ability the average weekly cost for a resident in a village community setting was \$1,377. This was less than the average adjusted cost reported for a resident in residential campus provision \$1,433, which in turn was less expensive than the comparable cost for a resident in dispersed housing was \$1,651. Staffing ratios were significantly higher across all staffing levels in dispersed housing schemes (1.7:1) than in NHS residential campuses (1.3:1) and village communities (1.4:1).

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<sup>6</sup> The study also includes a sample of persons resident in the family home but this group was excluded from the costing evaluation.

<sup>7</sup> The costing data gathered for this study were originally in UK sterling currency but have been converted to US dollars for publication in US publications. Figures are quoted as per their presentation in respective journals.

From a quality perspective, NHS residential campus settings were not preferable over village communities or dispersed housing on any indicator of quality. Distinct benefits were identified for dispersed housing schemes (e.g. choice, social networks, integration, and recreation activities) and village communities (e.g. social networks, reduction in risk, and scheduled activities). It is interesting to note that additional analyses using matched samples from each residential setting revealed that differences in the total cost between dispersed housing (\$1,425) and village community settings (\$1,245) were not statistically significant.

Emerson *et al.*, (2000b) further examined quality and costs for a matched group of residents with severe and complex needs resident in NHS residential campus settings and dispersed housing settings. Staffing levels were 115% higher in dispersed housing (2.8:1) when compared with NHS campus settings (1.3:1). This differential is reflected in the significantly higher weekly costs reported in dispersed settings for this population (direct staffing costs £756; total costs £1,218) when compared with NHS residential campus costs (direct staffing costs £500; total costs £952). Statistical analyses revealed that differences in staffing costs were the sole contributor to the overall difference in total costs. No differences were reported between the two residential models on other costs including administration, overheads, non-staffing running costs, capital costs and resident contribution costs.

Despite the difference in staffing ratios across the two settings, and the accompanying costs, no difference was reported between observed levels of staff contact with residents (11% in residential campus settings; 15% in dispersed housing). The finding reflects a substantial evidence base indicating a very weak relationship between staff ratio and staff contact. The results pertaining to resident outcomes in the present study indicate that, in general, support provided in dispersed housing resulted in a markedly higher quality of life for residents.

Further statistical analyses of the data emanating from this study was undertaken to explore quality and cost of different models of community-based living (Emerson *et al.*, 2001). Three community living options were identified; supported living, small group homes (1 to 3 co-residents) and large group homes (4-6 co-residents). Average weekly costs, when adjusted for level of ability did not differ between supported living (\$1,785), small group homes (\$1,684) and large group homes (\$1,591). The findings are consistent with other research indicating that for similar costs, supported living offers distinct advantages in the areas of choice and community participation over group home accommodation (Howe *et al.*, 1998). Staffing ratios were reviewed in each setting and revealed that supported living settings had higher overall staffing levels (2.1:1) and care staff levels (1.7:1) than those in small group homes (total staff 1.6:1, care staff 1.3:1) and larger group homes (total staff 1.7:1, care staff 1.2:1). Senior care staff levels did not differ across the three settings.

In one of the latter publications emanating from this extensive study, Hallam *et al.*, (2002) conducted an in-depth examination of the weekly average total service package cost for residents across the three residential models examined in the study. Weekly costs for those residing in village campus settings were calculated at £784, for those in NHS residential campus settings at £1,018 and for residents in dispersed housing at £1,039. These costs were further broken down to total accommodation costs, day activity costs and hospital and community services costs. Accommodation and day costs comprised between 97% and 98% of the total care package cost per resident across the three models. Hospital and community services comprised the remaining element of costs, and perhaps unsurprisingly, were highest among those resident in dispersed housing.

Further analyses were undertaken to explore the relationship between these costs and resident and service model characteristics. Generally, more costly services were associated with residents who were more likely to be dependent, male, younger, and exhibit challenging behaviour. Factors of the residential settings that were associated with higher costs included a fewer number of co-residents and the presence of nursing staff.

Residential management practices were also examined in terms of their impact on costs. Procedures such as person centred planning and activity planning were associated with higher costs. Higher costs were also associated with less sophisticated training and supervision of staff, a finding that was interpreted by the authors as 'counter-intuitive'. Finally, higher costs were associated with higher levels of 'depersonalisation', the extent to which settings have institutionalisation processes. In combination, the findings suggest that higher costs do not necessarily translate to better quality outcomes for residents.

It is worth noting in the context of the present review that the authors concluded that despite their undeniable focus on service costs, "*under most circumstances, costs-only decision making is dangerous, just as outcomes-only decision making is inadvisable*" (Hallam *et al.*, 2002; p.403).

Clearly, the residential study outlined above provides one of the most comprehensive datasets addressing the complex issue of the relationship between quality outcomes and costs in residential settings. This is evidenced by the use of this data in the determination of national unit costs discussed above (Curtis, 2007) and by the emphasis this research is given in *Valuing People*, the UK's first White Paper on people with intellectual disabilities in 30 years (Department of Health, 2001).

Findings from this study have stimulated much debate in the UK, most especially regarding the option of village community settings for people with disabilities. These settings typically comprise a cluster of living unit and other resources, (such as day centres or shops) that are physically segregated from the wider community. The finding that these settings are less expensive than either NHS residential campus or dispersed housing has generated debate about the appropriateness of this type of residential model for people with disabilities. At issue is the level of quality outcomes experienced by residents in village communities.

In response to this debate Emerson (2004) conducted a more detailed investigation of 'cluster housing'. Cluster housing was defined as three or more houses located as part of a campus development with an on-site day centre or three or more houses in a 'dead-end' street. The study involved a comparison of quality outcomes for n=169 residents in cluster housing and n=741 residents in dispersed housing. After adjusting for resident characteristics, some disadvantages were associated with this model. People living in cluster housing were, for example, reported to live in larger less staffed settings, to experience more inconsistencies in their residence due to a turnover of short-term residents and casual staff, to be more likely to experience restrictive practices such as sedation and restraint and to participate in fewer social and leisure activities. Emerson concluded '*there appear from our data to be few potential benefits of living in cluster housing*' (Emerson, 2004, p.195). Furthermore, no evidence was found to support the contention by those who espouse cluster accommodation that it provides a 'connected community' for residents. Emerson concluded that it is difficult to justify the apparently 'segregationalist policies' underpinning cluster housing.

More recently, research has turned to explore the quality and cost of residential care provision for people with challenging behaviour. Robertson *et al.*, (2004) conducted the first quality and cost comparison of community-based residential provision for persons with challenging behaviour. Cost and quality data were compared for 25 residents in congregate community-based settings (defined as residences where co-residents also present with challenging behaviour) with 25 matched residents in non-congregate community-based settings (either residing alone or with co-residents who did not present with challenging behaviour).

Costing data, converted to dollars for publication in a US based journal, indicated that accommodation costs were significantly higher in congregate settings (\$105,448) when compared with non-congregate settings (\$79,622). In contrast non-accommodation costs were higher in non-congregate settings (\$13,385) than congregate settings (\$7,293); this difference was attributed to more expensive day services. Overall, total costs were however significantly more expensive in congregate (\$115,830) than non-congregate settings (\$96,010).

Staffing levels were reported in this study and reveal that while senior care staff ratios were the same in both settings (0.5:1), higher total staff ratios and care staff ratios were observed in congregate settings (2.6:1 and 2.1:1 respectively) when compared with non-congregate settings (1.9:1 and 1.4:1 respectively). The authors conclude however that the higher level of staffing in congregate settings did not translate into better quality outcomes for these residents. In general, residents in congregate settings were more likely to be prescribed psychoactive medication, to be subject to restrictive practices such as restraint, to experience a reduction in mental health and to have more restricted day activities than their counterparts in non-congregate settings. The authors conclude that congregate settings, albeit contrary to Government policy, are currently being provided as residential options for persons with challenging behaviour. If the rationale is that these models foster expertise among staff, the diminished quality outcomes reported for residents in this study suggest that there is little evidence to support this conjecture.

Knapp *et al.*, (2005) conducted a large scale comparison of quality and costs for n=930 residents in a variety of residential settings. The average total weekly cost per resident (at 1996/1997 prices) was £692, of which £588 was accommodation costs, £75 was day care costs, £22 was professional or community costs and £7 was for acute health care costs. Comparison of costs across service providers revealed that the cost of provision in NHS settings (including long-stay hospitals, hostels, or residential care in ordinary housing) was higher (average weekly cost £779) than in private or voluntary settings (average weekly cost £532). The authors suggest that the higher level of need and challenging behaviour of those in receipt of NHS provision contribute to the higher costs observed in these settings. In addition, the authors suggest that higher staffing costs in NHS facilities might reflect higher staffing ratios, more qualified staff, or more highly paid staff within the NHS sector. Staffing costs and ratios are not defined within the paper.

In examining the variation in costs per resident (ranging from £220 to £1,570 per week) Knapp *et al.*, (2005) identified resident characteristics (e.g. level of ability, presence of challenging behaviour, age) and residential factors (e.g. service provider sector, size of residence) as predicting one third of the variation in costs per resident. While the relationships are complex, higher costs are associated with greater level of disability and larger statutory service provision. These findings support those previously (Beecham *et al.*, 1997; Cambridge *et al.*, 2002) indicating that public sector community accommodation was more costly than private or voluntary accommodation. The authors comment '*overall and in line with most other studies and with the findings presented here, roughly one third of the observed variation in weekly cost could be explained by these factors*' (p.304).

The final study in this selection of cross-sectional publications was recently undertaken by Felce *et al.*, (2008). The study comprised a comparison of quality and costs for n=35 matched individuals resident in fully staffed group homes and semi-independent living. While staffing ratios per se are not reported, the average staff hours per resident was compared across the two residential models. The number of staff hours in group homes (76.8) well exceeded that reported for semi-independent living (13.3).

Quality outcomes varied with those in semi-independent living reporting poorer outcomes than group home residents on money management, health screening and number of group community activities. These residents however reported better quality outcomes when compared with group home residents in terms of larger social networks, engagement in household activities, and opportunities to express choice.

Regarding costs, the total weekly cost of care was higher for fully staffed residences (\$1,539) when compared with semi-independent residences (\$639.2). The breakdown of these costs into accommodation (e.g. staffing and overheads) and non-accommodation costs (e.g. community-based input, health services) revealed that both costs were higher for fully staffed residences. The authors conclude that given the specific advantages attributed to both

residential models they are unable to reach the straightforward conclusion of Stancliffe & Keane (2000) that semi-independent living delivers better outcomes for residents at a lower cost. The findings do however suggest that higher staff ratios are associated with residents exercising less choice. The authors also suggest that outcome differences in semi-independent living, such as greater money management problems and less health screening, may be deemed to reflect greater levels of self-determination and choice. Semi independent living would seem therefore to offer certain advantages over group home living at lower costs.

While the review above provides only a selection of the many cross-sectional studies evaluating the quality and cost of residential provision for people with disabilities, some common themes emerge.

NHS statutory facilities were typically found to be more costly than other forms of residential provision but delivered poorer quality outcomes for residents. In contrast, dispersed community-based housing options were more costly than NHS provision but were identified as providing distinct benefits for residents. Among the community-based residential options reviewed, supported living was identified as being most 'cost effective', that is, as providing distinct quality outcomes for residents in comparison with group home setting but at a similar or reduced cost (Felce *et al.*, 2008; Emerson *et al.*, 2001).

Village community settings have been identified as being less costly than dispersed community-based options (Emerson *et al.*, 2000a). Despite the distinct advantages associated with this model of residential support, it attracts controversy and debate. Most recently, the advantages of this form of support have been challenged (Emerson, 2004).

Level of need is associated with greater cost (Knapp *et al.*, 2005; Hallam *et al.*, 2002). Studies examining residential provision for those with complex needs and challenging behaviour (Emerson *et al.*, 2000b; Felce *et al.*, 2000; Robertson *et al.*, 2004) suggest that while community-based provision may be more costly than institutionalised or congregate care, the increased costs are associated with better quality outcomes for this group. All studies comment on the tenuous relationship between staffing ratios and quality outcomes noting that higher staffing ratios do not translate to better quality outcomes for residents.

### **5.3 3. Non-UK studies using a variety of methodologies.**

The studies presented in this section are a sample of non-UK studies of residential cost and quality that employ unique costing methodologies. In many cases these methodologies constitute 'top down' approaches whereby costs are typically garnered from administrative databases. The findings are briefly reviewed.

Howe *et al.*, (1998) in a matched comparison of persons in Oregon resident in supported living (n=16) and more traditional residential settings (e.g. group homes; n=16) reported no significant difference in the public support costs associated with each model of residence (average monthly costs are \$2,144.19 and £2,066.04 respectively). Average hours of staff support per week were higher in supported living (average 12.65) than group home accommodation (average 8.99). In addition, quality outcomes such as engagement in community activity and larger social networks were associated with supported living. The authors conclude that, for similar costs, supported living offers greater quality outcomes in choice and community participation than more traditional models of support. These findings, albeit in a different jurisdiction, and using a different costing methodology, are consistent with those reported by Emerson *et al.*, (2001) above.

A similar comparative study of group homes and supported living options was undertaken in Australia by Stancliffe and Keane (2000). Comparative data for a matched group of residents in group home (n=27) and semi-independent living residents (n=27) revealed that in all cases where differences in quality outcomes were reported between the groups, residents in



supported living accommodation achieved better quality outcomes. In a departure from the findings from Howe *et al.*, (1998) and Emerson *et al.*, (2001) however this study reported considerably higher costs from group home residences \$64,105 when compared with semi-independent models (\$14,602). The cost differential is reflected in the markedly higher staffing levels in group homes when compared with semi-independent models; on average group home residents received 300% more paid staff support per week than those in semi-independent living. The study concludes that from both a quality and a cost perspective, semi-independent living was found to be favourable to group home accommodation.

Rhoades & Altman (2000), using an extensive US database containing data on a nationally representative sample of people with intellectual disabilities in residences of three or more, reported that costs were related to level of functioning. Consistent with previous research, residents with greater levels of need had significantly more expenses costs (Hallam *et al.*, 2002; Knapp *et al.*, 2005).

Size of residential facility was also found to be related to cost. The average daily cost of residents in smaller settings (as defined by 3-15 residents) was less than the average cost observed in larger facilities (>16 residents). This pattern was observed across 'for profit' organisations (average daily cost \$36 in smaller settings, \$41 in larger settings), 'non profit' organisations (average daily cost \$51 in smaller settings, \$62 in larger settings) and government owned settings (average daily cost in smaller settings \$75, larger settings \$119). The pattern of cost reflects the relationship between level of need and size of facility; that is, larger residential facilities had a higher number of residents with greater needs. The greater health services availed of in larger settings was also identified as being a main contributor to the higher charges reported in these settings. Attempts to interpret these findings in light of the UK studies presented previously are somewhat hampered by the classification of 'small' settings as providing supports to between three and 15 residents. This range spans a vast array of typical residential supports provided in the UK including independent living for three residents, group homes for less than five residents, and registered care homes with nursing support for ten or less residents. As such any attempt to draw comparisons between findings would be unlikely to compare 'like with like'.

Spreat *et al.*, (2005)'s matched comparison of n=174 pairs of people with intellectual disabilities resident in community settings (Waiver funded) and institutional settings (ICF/MR funded) in Oklahoma revealed that the average annual cost in community settings (\$123,384) was significantly less expensive than that determined for those in institutional settings (\$138,720). Given the cross-sectional design of the study, it contradicts the findings from similar studies undertaken in the UK where community care costs have been reported to be higher than congregate settings costs (Felce *et al.*, 1998; Emerson *et al.*, 2000a; Emerson *et al.*, 2000b; Hallam *et al.*, 2002). Spreat *et al.*, (2005) propose that while staff wages are considerably higher in institutional settings in the US, the more favourable staffing ratios in community-based settings would suggest that community costs should exceed institutional costs. One possibility is that institutional costs will increase as the deinstitutionalisation process rolls out; essentially, the economies of scale benefit will diminish.

A finding that was consistent with UK research was that quality outcomes regarding community participation were greater for those in community-based settings. An unexpected finding was the higher levels of work and pre-work activity observed in institutionalised settings. The authors note that information on daily activities was unavailable for almost half the community-based sample and therefore may reflect a growing trend towards volunteer and recreationally based activities which were not captured in data collection.

An interesting finding from this study was the weak relationship observed between institutional and community costs. The implication of this finding is that it suggests there is no evidence that support needs are related to the cost of service provision. The authors comment that the finding is '*perhaps the most disturbing of our study*' (p.26).

The final study in this selection was conducted by Head & Conroy (2005) and does not compare the cost of residential settings per se, but rather the mechanisms by which supports are funded. The study outlines a Robert Wood Johnson Foundation national demonstration project which awarded nineteen states funding to determine whether changing the balance of funding in favour of people with disabilities could result in greater quality outcomes at no greater cost than more traditional funding mechanisms. Head & Conroy (2005) reviewed the data gathered on behalf of n=70 residents in Michigan as they transferred from traditional sources of funding in 1998 to individualised budgets in 2001. Individualised budgets allowed residents to contract directly with service providers and purchase the supports they required. Alternatively residents could choose to have a 'fiscal intermediary' assist in the purchasing of their chosen services. These fiscal intermediaries were appointed by the Community Mental Health Service Programme (CMHSP), the organisation charged with operating Michigan's developmental disability services. The fiscal intermediary would therefore hold the funds allocated to residents and make payments for services requested by the resident.

To examine whether changing the balance of funding toward direct payments could result in greater quality outcomes at no greater costs, quality and costing data were gathered. Costing data revealed a 16% decrease in adjusted costs from an average public cost per annum of \$67,322 in 1998 to \$56,778 in 2001. The pattern of cost reduction was greatest for those with traditionally high levels of expenditure. That is, the people with the highest initial costs report the greatest cost savings. This average trend however does conceal the finding that for some residents, costs increased following the introduction of individualised budgets. This finding may reflect the fact that these residents were underserved prior to using individualised budgets. The average decrease in costs was associated with gains in quality outcomes such as self-determination. Head & Conroy suggest possible factors which result in this reduction in the cost of service delivery. Firstly, individuals may no longer be in receipt of unwanted services. Secondly, individuals have greater control over the flexibility with which they receive and fund services. Thirdly, individuals were able to negotiate costs with service providers and seek more cost effective providers if required. Finally, the direct nature of purchasing supports eliminates administration costs where these services are carried out with an agency. The authors note that these 'win win' situations are reflected in evaluations conducted in other states where comparison control groups were also examined (Conroy *et al.*, 2002).

In combination the studies presented above provide an insight into the cost of residential provision in jurisdictions beyond the UK. The methodologies used to determine these costs differ from those used in the UK and are typically drawn down from administrative databases. Despite these differences in jurisdiction and methodology some robust findings emerge. Supported or semi-independent living is typically reported as providing better quality options for residents at either comparable or lower costs than group home settings. The move towards individualised budgets for which an evidence base is only emerging, suggests that individualised and targeted supports may provide optimal benefits for residents at a reduced cost. The relationship between cost and level of need however must be acknowledged. Those with greater levels of need incur higher costs for supports. This is particularly relevant during the deinstitutionalisation process as those with greater levels of need are typically the last to be offered community living options. The move towards community living should however be available to all, irrespective of level of need, given the extensive body of evidence attesting to the superior quality outcomes observed in community-based settings.

## **6 Recommendations outlining how residential cost and associated quality outcome data could be validly gathered in Ireland if required**

While numerous methodologies have been employed to determine the cost of residential provision for people with disabilities, the review above has clearly shown how one methodology has dominated the peer-reviewed literature in the UK. The Beecham & Knapp (1992) and Knapp (1995) methodology outlined above has provided robust estimates of cost across multiple residential settings. It has been extensively validated and contributes to the UK national unit cost data published annually by PSSRU. Recall that the unit cost data is based on the extensive quality and outcomes study led by Professor Eric Emerson. This data, collected in 1999 is still employed almost a decade later to determine the unit cost of health and social care for group home provision, village community provision, NHS residential provision and support living schemes. It is also worth noting that a relatively modest sample size of n=500 residents was sufficient to provide reliable data to determine these costs. The village community data cited in the 2007 annual unit cost figures, for example, is based on data from only 86 residents.

As stated previously, costing data using this methodology was collected on behalf of (n=125) Irish residents in group home and village campus settings (Walsh *et al.*, 2000). The reliability of this data is may now be at issue given the change in currency (from punt to euro) and the change in disability funding in the preceding years. Gathering this data afresh would produce valid costing estimates across different residential models (including more contemporary options such as supported living). In addition, the data would provide a benchmark for the construction of unit cost data similar to that calculated annually by PSSRU. The collection of this data should not however occur in isolation. As the review above has outlined, the cost of service provision should be accompanied by informative data on the associated quality of service provision. As Mansell *et al.*, (2007) comment *the archetypal institution is cheap to run* (p.43). Standardised quality of life outcome measures are plentiful and most notably, have been recently reviewed by NDA in the 2007 publication "*Supported Accommodation Services for People with Intellectual Disabilities: A review of models and instruments used to measure quality of life in various settings*".

Data from the National Intellectual Disability Database and the National Physical and Sensory Database estimate that almost 4,000 persons with disabilities are live in settings with ten or more co-residents. This size of setting is defined by the *HSE Working Group on Congregate Settings for Persons with Disabilities* as a 'congregate' setting. The transfer of this population to community-based living, and its associated quality of life benefits, should be informed by accurate and timely data.

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