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Living Arrangement Options for People with Intellectual Disabilities: A Scoping Review

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FROM CONGREGATED TO COMMUNITY LIVING

MOVING AHEAD

Living Arrangement Options for People with Intellectual Disability: A Scoping Review

TRINITY COLLEGE DUBLIN

HRB
Health Research Board

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1. Overview

1.1   This is one of a pair of reports prepared for the *Moving Ahead Project*. Its partner policy review, *Mapping the National Intellectual Disability Landscape* (Linehan et al., 2014a), outlines current disability services, practices and policies in Ireland. This rapid scoping review provides a brief overview of national and international research exploring living arrangement options for people with intellectual disabilities.

1.2   Rapid scoping reviews present a summary of key research; in contrast to traditional academic reviews, they do not attempt a comprehensive, formal synthesis of evidence but rather collate findings from a range of approaches, aiming to identify key themes and gaps and to be useful for policy makers (Arksey & O'Malley, 2005). The report does not therefore aim to be comprehensive, but rather to provide a brief overview of evidence in this broad field of study.

1.3   The scoping review commences with pioneering studies that highlighted the poor quality of life experienced in institutions; next, explores the impact on quality of life of moving to the community; and then addresses community living options for people with intellectual disabilities. The preferences of people with disabilities and family members are considered, as are the costs of various living options. The review then turns to key issues in supporting people with intellectual disabilities to enjoy an optimal quality of life: (i) supporting people with high levels of need, such as those with behaviours that challenge, with profound and multiple disabilities, and older people; (ii) facilitating social inclusion; and finally (iii) supporting individuals to achieve optimal independence through active support and robust advocacy. Next, the review considers the role of organisational factors in deinstitutionalisation. It concludes by noting significant barriers and facilitators that need to be addressed to achieve change in disability services, and by identifying patterns of regional differences in implementing community living, internationally and in Ireland.

OVERVIEW OF FINDINGS

1.4   In the 20th century, seminal studies revealed the devastating nature of institutional life. Since deinstitutionalisation began, a large body of research has measured quality outcomes when people with intellectual disabilities move to smaller, more personalised, community-based living. Major academic reviews, summarising nearly 300 international studies since 1977, show that improvements are found in most aspects of people's lives, such as in their personal skills, social relationships, and opportunities to exercise choice. If outcomes and costs are compared for people with similar support needs, the quality of community living options is considerably higher, yet there is no evidence they are more expensive than larger congregated settings. A clear picture therefore favours community rather than congregated living.

1.5   However, deinstitutionalisation involves more than simply closing institutions. This is seen in the less cohesive but growing body of 'post-deinstitutionalisation' research, which explores the challenges of providing quality supports in local communities. Although few differences are found when comparing different models of community support, the differences that do exist often favour more personalised living and supports.

1.6   The overall trend of findings indicates that people with intellectual disabilities experience better outcomes in the community, whatever their age or level of disability. However, the type of support provided mediates the quality of outcomes achieved. Many individuals living in the community experience extended periods of inactivity, and staff often prioritise caring over active

support and social inclusion. This may explain why, despite decades of deinstitutionalisation, many people with intellectual disabilities, despite being physically present in their communities, remain socially excluded.

1.7 The challenge of introducing large-scale change in disability services is under-researched. International research from a range of human services (e.g., health, social work, welfare and education) demonstrates that every facet of an organisation is involved in successful change, although some (such as the organisation's aims and people's stated roles) are more visible than others (such as its culture, metaphors, and emotions). Factors that need to be considered when creating change include organisational culture; leadership and staff responses; implementation plans; and systems of accountability including structures of public governance.

1.8 Finally, the review turns to the question of regional disparities in deinstitutionalisation. This rarely researched topic was recently examined in Ireland, drawing on the National Intellectual Disability Database. This revealed that national figures mask stark regional differences: in some regions the proportion of people supported in congregated settings has reduced by a third in the last decade, whereas in other regions it has actually increased. The cause for such differences is unknown, and this question provides the rationale for the Moving Ahead project.

OVERVIEW OF REVIEW METHOD

1.9 To cover the wide range of territory necessary for this scoping review, we drew on multiple research fields. Where possible, we sourced widely cited major reviews and evaluations, or those conducted by international intellectual disability experts. As deinstitutionalisation has been researched extensively, we drew on seven major academic reviews (of studies worldwide since the 1970s; see Section 3). We also consulted three major recent reviews and evaluations of deinstitutionalisation processes, conducted by international leaders in disability studies, to identify current perspectives on barriers and facilitators for deinstitutionalisation and provision of quality community supports (Section 12).

1.10 We added to these major reviews with a rapid scoping process as recommended by Arksey and O'Malley (2005): searching electronic databases; hand searching reference lists and key journals; consulting knowledge networks and relevant agencies; and consulting with stakeholders[1]. The less extensive body of 'post-deinstitutionalisation' research was identified through this process (Sections 4-9). Finally, as there are few studies of the process of organisational change in deinstitutionalisation, we focused our scoping searches on studies of organisational factors in the broader fields of health care and social work (Sections 10 & 11).

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[1] *Details are available on request from Dr Christine Linehan, Principal Investigator, University College Dublin.*

2. Deinstitutionalisation

If people with intellectual disabilities are to lead a life that is comparable to other citizens, then the policy to close institutions and replace them with community-based services is the correct one.

(Clement & Bigby, 2008, p.iii)

2.1   Deinstitutionalisation is the most significant policy development for people with disabilities in the late 20th century (Bigby & Fyffe, 2006; Kozma, Mansell & Beadle-Brown, 2009; Mansell & Ericsson 1996). As defined by the 2010 Consensus Statement of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD)'s Comparative Policy and Practice Special Interest Group,[2] deinstitutionalisation involves *"the gradual abandonment of large residential institutions and their replacement by small scale services to enable people to live well in the community"* (Mansell, Beadle-Brown with members of the Special Interest Research Group on Comparative Policy and Practice, 2010; p.104),

2.2   Deinstitutionalisation is an international right under the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006). Article 19 of the Convention recognises the *"equal right of all persons with disabilities to live in the community"*. The Convention specifies that individuals with disabilities have a right to choose where and with whom they live, and to receive supports to ensure they are not isolated or segregated from their community. Jurisdictions that adopt the Convention must ensure that community services and facilities are available equally for persons with and without disabilities.

2.3   There are multiple definitions of institutions. Many focus on the size of a facility and the profile of the people it supports. The European Commission, in commissioning research on the prevalence of institutional living in Europe, specified *'settings where thirty or more individuals live, of whom at least 80% have disabilities'* (Mansell, Knapp, Beadle-Brown and Beecham, 2007). However, others argue that the impact of institutional living is overlooked if one focuses solely on the numbers and profile of people, and that institutional living is reflected in attitudes, values, practices and frames of reference (Johnson & Marriott, 2009).

2.4   Indeed, there is some evidence that institutional practices have migrated to community settings (Varey, 2014). So that past mistakes are not repeated, by developing new community 'mini-institutions', we begin this review with a brief historical review of institutional settings and practices, and a reminder of the impetus for deinstitutionalisation among pioneering countries: the United States, the United Kingdom and Scandinavian countries (Mansell & Ericsson, 1996).

2.5   Institutions became widespread in the 20th century. At their peak in the 1960s, 194,650 individuals with disabilities in the US were living in state-run institutions (Lakin, Bruininks & Sigford, 1981, cited in Mansell & Ericsson, 1996), and 58,850 were living in hospital settings in the UK (Stevens, 2004). Scandinavian countries reached a peak in the 1970s when almost half of adults receiving services in Norway, approximately 5,500, were supported in institutional settings (Tossebro, 1996).

2.6   As institutions grew in number and scale, with hundreds or thousands of residents, the well-being of people confined in them became a cause for concern. In 1966, Russell Barton, an Anglo-American psychiatrist, coined the term 'institutional neuroses', observing that residents in psychiatric institutions displayed 'neuroses' beyond their original diagnosis, such as:

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[2] *https://iassid.org/*

"...apathy, lack of initiative, loss of interest more marked in things and events not immediately personal or present, submissiveness, and sometimes no expression of feelings of resentment at harsh or unfair orders. There is also a lack of interest in the future and an apparent inability to make practical plans for it, a deterioration in personal habits, toilet and standards generally, a loss of individuality, and a resigned acceptance that things will go on as they are - unchangingly, inevitably and indefinitely"

(cited in Reeves, Pringle, Campion, Fleetwood & Scully, 1966, p.350)

2.7 Barton identified features of institutional life that contributed to these behaviours: loss of contact with the outside world, disruptive behaviours managed with medication, 'enforced idleness' in socially and physically unstimulating environments, and authoritarian staff attitudes.

2.8 Pioneering research in the UK identified the effect of austere environmental conditions on residents' outcomes. In the 1950s, Jack Tizard and colleagues found that 16 children with intellectual disabilities who moved from a long-stay hospital to 'Brooklands', a community-based property, gained social skills that were not seen in the children who remained at the hospital setting (Tizard, 1960). The 'Wessex Experiment' provided further evidence of positive outcomes for children supported in smaller, locally-based services (Kushlick, 1976).

2.9 A series of exposés in the 1960s brought the issue of institutions to public consciousness. Erving Goffman's 'Asylums: Essays on the Social Situation of Mental Patients and other Inmates' (1961) provided a rare and harrowing insight into US institutional life. Similarly in the UK in the late 1960s and early 1970s, exposés revealed neglect, overcrowding, and staff indifference in hospitals such as Ely, Farleigh and Whittingham, indicating that such conditions were endemic and not, as some claimed, isolated or unusual (Martin, 1984). Of the exposés, arguably it was 'Christmas in Purgatory' that caused most outcry. This graphic photographic undercover exposé of five US institutions visited in 1965 by Burton Blatt and Fred Kaplan (1974) commenced with the words of Dante: *'Abandon all hope, ye who enter here'.*

2.10 In addition to scandals, two other factors drove deinstitutionalisation in the US (Braddock, Hemp, Bachelder & Fujiura, 1995). The civil rights movement mobilised people with disabilities to seek equal rights to those of non-disabled peers, and litigation by parents and by staff working in institutions questioned the constitutionality of segregated settings. Legal judgments such as the Pennhurst and Olmstead cases found, respectively, that institutional care was unconstitutional, and that individuals must be supported in the most integrated setting (Conroy & Bradley, 1985). These judgments relaxed the regulation that US State Medicaid health funding could only be applied to institutions, allowing it to be diverted to community settings (Lakin, Larson, Salmi & Scott, 2009).

2.11 Ideological factors were also key to deinstitutionalisation (Mansell & Ericsson, 1996). The principle of normalisation was a major factor in Scandinavia. First developed in the late 1950s, and articulated by Bengt Nirje (1969), normalisation holds that people with disabilities should experience the same rhythms to the day as others similar in age, gender and culture (Culham & Nind, 2003). To facilitate people to experience normality, it is society, and not individuals with disability, who must adapt (Tossebro, Bonfils, Teittinen, Tideman, Traustadottir, & Vesala, 2012). A half century later, this process culminated in legislation requiring all supports for people with intellectual disabilities to be provided through community services (Ericsson, 2000).

2.12 Wolf Wolfensberger brought a modified version of normalisation, Social Role Valorisation, to the US. Social Role Valorisation argues that people's well-being is largely determined by their social role. If people hold social roles deemed to be of value, they are likely to be positively appraised by members of their society. Those not holding valued roles have little opportunity to gain the acceptance of their peers (Wolfensberger, 2000).

2.13 In addition to pressures from institutional scandals, litigation, and ideological influences, another factor driving deinstitutionalisation was that of cost (Mansell & Ericsson, 1996). In Scandinavia and the US, the cost of institutional care was high, and would have become prohibitive if quality support was offered. Costs were also a feature of UK reform, but for a different reason. Community care was of considerably higher quality but was also more expensive than institutional care in the UK (Emerson et al., 2000); however, with the reorganisation of the National Health Service (NHS) in the 1980s, community social care finance was diverted from the NHS to social security departments. As a result, this revenue was available for community development initiatives.

2.14 Finally, the success of living arrangements in the community further drove deinstitutionalisation in these jurisdictions, even though early community-based homes were relatively large (Mansell & Ericsson, 1996). In the US, for example, the 'Intermediate Care Program' developed large-scale community facilities known as ICF-MRs (intermediate care facilities for people with mental retardation). These represent the 'first wave' of deinstitutionalisation (Bigby & Fyffe, 2006; Kushlick, 1976; Rotegard, Bruininks & Krantz, 1984). In the 1980s and 1990s, in a 'second wave' of deinstitutionalisation, larger community facilities were superseded by community 'group homes': typically fully staffed houses, dispersed in the community, supporting three to eight people with intellectual disability (Bigby & Fyffe, 2006; Ericsson, 1996).

2.15 Deinstitutionalisation was therefore supported by a sense of injustice for those living in institutions, sometimes fuelled by graphic and disturbing scandals; growing advocacy and rights-based movements combined with litigation in some jurisdictions; and the fact that many jurisdictions sought an alternative option, when faced with substantial costs of refurbishing and appropriately staffing institutionalised settings to achieve quality outcomes.

2.16 Currently, these jurisdictions are implementing a 'third generation' of supports for people with intellectual disabilities (Ericsson, 2000). Continuing the momentum for smaller-scale community living, they are developing highly individualised options, supporting people with intellectual disabilities to live in a place of their choosing, alone or with others. This model, known as 'supported living' in the UK, aims to counteract criticisms of group homes where personal choice is more limited (Mansell, 2006). The supported living model typically separates accommodation and social support services, encouraging individuals to become tenants of their own properties and enabling them to alter either of these services if they choose, without impacting on the other (Allard, 1996; Kinsella, 1993; Stevens, 2004).

2.17 Deinstitutionalisation advances in the UK, US and Scandinavia are now mirrored elsewhere and these trends have been captured in comparative studies. Developments in Europe, for example, were monitored in the IDRESNET (the European Intellectual Disability Research Network) and DECLOC (Deinstitutionalisation and Community Living Outcomes and Costs) projects (European Intellectual Disability Research Network, 2003; Mansell, Knapp, Beadle-Brown & Beecham, 2007). These suggest that despite progress towards community living in some countries such as the Netherlands, Ireland, Germany, Spain and Greece, institutional settings still provide substantial services (Mansell, 2006). Challenges also arise in former Soviet countries in Eastern Europe where poor quality institutions dominate (Mansell, Beadle-Brown & Clegg, 2004; Mansell et al., 2007). Some of the key findings from these and other studies examining the implementation of deinstitutionalisation are presented in Section 12.

2.18 The outcome of deinstitutionalisation for people with disabilities has received considerable research attention. The next section provides an overview of the key findings of these studies.

3. Quality Outcomes following Deinstitutionalisation

Generally, when people with intellectual disabilities are moved from institutions into smaller community-based services, there is an associated improvement in their quality and standard of life.

(Young, Sigafoos, Suttie, Ashman, & Grevell, 1998)

3.1   This section provides an overview of 'deinstitutionalisation' studies that have examined effects on quality of life for people with intellectual disabilities who move to smaller, community-based settings. Studies either compare individuals living in community-based housing to a matched group who remained in institutions ('cross-sectional studies'), or compare the same group of people before and after they leave institutions for life in the community ('longitudinal' studies).

3.2   Many studies take a 'quality of life' approach, assessing the impact of living arrangements on emotional well-being, social relationships, social inclusion, and self-determination among others (Schalock et al., 2002;cSiska & Beadle-Brown, 2011; Walsh et al., 2010).

3.3   Before reviewing this evidence, two factors that have a major impact on quality outcomes for people with intellectual disabilities must be considered. People with more support needs typically experience poorer outcomes than people with fewer support needs, no matter where they are supported. For example, some key benefits enjoyed by people with disabilities in the community, such as social inclusion, meaningful activity and choice, are limited for individuals with lower levels of ability (Beadle-Brown et al., 2007). Similarly, individuals who engage in behaviours that challenge, or who have fewer adaptive behaviours, are often excluded from household and community activities (Felce & Emerson, 2001). Thus, level of ability has a powerful effect on the outcomes people experience, functioning as a 'confound' in research (Beadle-Brown, Mansell & Kozma, 2007; Smith, Morgan & Davidson, 2005).

3.4   Second, staff factors also have a strong influence on individuals' quality of life. Staffing ratios, training, and, critically, the manner in which support is provided, all combine to influence quality outcomes experienced by people with disabilities (Mansell & Beadle-Brown, 2012; Felce & Perry, 2007). Staff-related findings are discussed in more detail in Section 10.

3.5   To outline the evidence for the impact of deinstitutionalisation on quality of life, seven major reviews of the academic literature, covering 280 studies worldwide, are summarised below. The studies were conducted between 1977 and 2010, most (but not all) in the US, Australia, the UK, and Ireland (Table 1). The reviews address 17 quality outcomes that improve, remain stable or deteriorate following moves to the community, from which we present a selection.

3.6   The outcomes support the compelling assessment by Prof. Jim Mansell, a leading international authority in disability, that there is "a relatively clear picture. Research has consistently shown that community-based services are better than institutions" (Mansell, 2005; p. 23).

Table 1: Academic Reviews examining Quality Outcomes for People with Intellectual Disability following Deinstitutionalisation

Author & Year	Paper
Larson, S., Lakin, C., Hill, S. (2012).	Behavioural outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: US studies from 1977 to 2010. *Research and Practice for Persons with Severe Disabilities, 37*(4), 235-246.
Chowdhury, M., & Benson, B.A. (2011).	Deinstitutionalization and quality of life of individuals with intellectual disability: A review of the international literature. *Journal of Policy and Practice in Intellectual Disabilities, 8*(4), 256-265.
Walsh, P. N., Emerson, E., Lobb, C., Hatton, C., Bradley, V., Schalock, R. L., & Moseley, C. (2010).	Supported accommodation for people with intellectual disabilities and quality of life: An overview. *Journal of Policy and Practice in Intellectual Disabilities, 7*(2), 137-142
Kozma, A., Mansell, J., & Beadle-Brown, J. (2009).	Outcomes in different residential settings for people with intellectual disability: A systematic review. *American Journal on Intellectual and Developmental Disabilities, 114*(3), 193-222.
Kim, S., Larson, S. A., & Lakin, K. C. (2001).	Behavioural outcomes of deinstitutionalisation for people with intellectual disability: A review of US studies conducted between 1980 and 1999. *Journal of Intellectual & Developmental Disability, 26*(1), 35-50.
Young, L, Sigafoos, J., Suttie, J., Ashman, A., & Grevell, P. (1998).	Deinstitutionalisation of persons with intellectual disabilities: A review of Australian studies. *Journal of Intellectual & Developmental Disability, 23*(2), 155.
Emerson, E., & Hatton, C. (1996).	Deinstitutionalisation in the UK and Ireland: Outcomes for service users. *Journal of Intellectual & Developmental Disability, 21*(1), 17-37.

GAINS IN QUALITY OUTCOMES FOLLOWING DEINSTITUTIONALISATION

3.7   People with intellectual disabilities experience many benefits when moving from institutions to the community. Their personal skills increase and they are more engaged in activities. They have more contact with friends, wider social networks and more community presence. They experience greater choice, satisfaction and quality of life. There is some evidence for changes in material well-being and employment, and indications that psychological well-being does not decrease. A selection of factors is presented here.

3.8   **Adaptive behaviour or 'personal skills'** encompasses self-care, daily living, communication and social skills (Walsh et al., 2007; Young et al., 1998). Almost all studies show increases on moving to community settings (Kim, Larson & Lakin, 2001; Walsh et al., 2010; Young et al., 1998). However, gains plateau over time (Emerson & Hatton, 1996), suggesting they may be due to greater opportunities in community settings, rather than development of personal skills.

3.9   **Family contact:** Young et al. (1998) note five Australian papers report that people with intellectual disability had higher levels of contact with family and/or friends when living in community locations. Kozma et al. (2009) similarly report that large-sized residences were associated with less family contact. These authors also report, however, that family contact was related less to the type and size of living arrangement than to distance from the family home and personal characteristics such as level of ability and parental age. Findings indicate

that the lack of family contact seen in institutional settings may reflect a combination of the characteristics of the people supported in them and more isolated locations.

3.10   **Social networks and friendships:** There is consistent evidence that people living in community settings have larger social networks and more friendships (Kozma et al., 2009, Walsh et al., 2010; Young et al., 1998). However, some findings indicate that social contact was infrequent, and non-family relationships were 'superficial or non-existent' (Emerson & Hatton 1996, p.28). Friendships and social networks were greater where supported people had adaptive skills (Kozma et al., 2009) or a tenancy agreement (Walsh et al., 2010); and were more restricted where supported people had behaviours that challenge (Kozma et al., 2009).

3.11   **Community presence and participation:** Strong evidence indicates that living in community-based accommodation results in greater community presence, participation and integration (Emerson & Hatton, 1996; Kim et al., 2001, Kozma et al., 2009; Young et al., 1998). However, active participation is often not achieved, particularly for those with high support needs (Baker, 2007). The challenges of realising full community inclusion are revisited in Section 8.

3.12   **Satisfaction:** Individuals with intellectual disability and their family members were more satisfied with individuals' life and lifestyle, and with services received, after a move to the community (Emerson & Hatton, 1996; Kozma et al., 2009; Walsh et al., 2010; Young et al., 1998). This included families who had initially been sceptical of a move (Kozma et al., 2009).

3.13   **Choice and self-determination:** People with intellectual disabilities in community settings experienced greater choice and self-determination in day-to-day decision-making (e.g. when to eat) and feelings of control and autonomy in their lives (Emerson & Hatton, 1996; Kozma et al., 2009; Walsh et al., 2010). However, this was related to more routine daily activities and typically did not extend to significant life decisions (Emerson & Hatton, 1996).

3.14   **Quality of Life (QoL)** is "general well-being that comprises objective descriptors and subjective evaluations of physical, material, social and emotional well-being together with …personal development and purposeful activity all weighted by a personal set of values" (Felce & Perry, 1995, cited by Chowdhury & Benson, 2011, p. 257). Kozma et al. (2009) found greater QoL after moving to the community, but considerable variation with individual characteristics and staff practices. Chowdhury and Benson (2011) reviewed QoL in 15 studies (1980-2009) using standardised quantitative measures, and found positive effects on choice, engagement in activities and interaction with staff and residents. As with adaptive behaviour, however, many reported a 'plateau effect' within a year.

3.15   **Engagement** is "appropriate non-social activity (such as participation in leisure activity, personal care, domestic activity or an appropriate response to a formal programme) or social interaction between the user and others (usually staff and other service users)" (Emerson & Hatton, 1996, p. 21). Of 30 studies, 23 found engagement increased after deinstitutionalisation, and none reported a decrease.

3.16   **Material well-being:** Two reviews reported on aspects of material well-being. Walsh et al. (2010) reported a modest increase in personal income and possessions following a move to community settings. Emerson and Hatton (1996) examined physical surroundings, reporting that individuals found community-based environments more pleasing.

3.17   **Employment:** There is limited evidence that employability increases when living in the community (Walsh et al., 2010).

3.18   **Staff contact**: Emerson and Hatton (1996), reviewing 29 UK and Ireland studies, noted that 23 found staff-initiated contact with individuals with intellectual disability increased after a move to

community settings, or when moving to any less institutional settings (e.g. from hostel/unit to staffed house). No study reported decreased staff contact after a move to the community.

3.19 **Emotional well-being and mental health:** There was no evidence that moving to the community resulted in psychological trauma; nor that mental health difficulties increased (Kozma et al., 2009). Walsh et al., (2010) found no evidence that emotional well-being and mental health varied systematically by residential setting.

QUALITY OUTCOMES REMAINING STABLE OR DETERIORATING FOLLOWING DEINSTITUTIONALISATION

3.20 Despite many gains experienced by people with intellectual disabilities in the community, there are some areas where no improvements, or indeed poorer outcomes, have been reported.

3.21 **Mortality:** Kozma et al. (2009) report that, in a series of 10 studies conducted in California, 6 found higher mortality in individuals moving to the community (Shavelle & Strauss, 1999; Strauss & Kastner, 1996; Strauss, Shavelle & Baumeister, 1998). The authors suggest 'relocation syndrome' and insufficient access to health care is the cause. These findings have not been replicated elsewhere (Conroy & Adler, 1998; Lerman, Apgar & Jordan, 2003; O'Brien & Zaharia, 1998). More recently, however, a population-based Confidential Inquiry in southwest England reviewed deaths in 2010-2012 (Heslop et al., 2013), and found that 37% deaths of individuals with intellectual disabilities were due to factors associated with poorer access to health care (compared to 13% for the general population). Contributory factors suggested by the inquiry included inappropriate accommodation; problems with advanced care planning; not adjusting supports as needs changed; carers not feeling listened to; problems following the Mental Capacity Act; lifestyle choices; and delays in treating health problems (Heslop et al., 2013).

3.22 **Physical health:** Community living is associated with poorer health behaviours (smoking, diet, activity), leading to poorer physical health including obesity (Kozma et al., 2009; Walsh et al., 2010). Some researchers have suggested that these are inevitable outcomes of increased choice (Felce et al., 2008) and may indeed be interpreted as people with intellectual disabilities experiencing the 'dignity of risk', which Perske (1972) considered an essential part of community life.

3.23 **Behaviours that challenge** are "culturally unusual or unacceptable behaviours, such as self-injury or aggression, that place the health or safety of the person or others in jeopardy or are likely to lead to the person being excluded or denied access to ordinary community settings" (Emerson & Hatton, 1994, p.17, cited in Kozma et al., 2009, p. 204). Here, the pattern of findings varies: moving to community living has been associated with decreased behaviours that challenge, but also with no change or an increase (Kim et al., 2011; Kozma et al., 2009; Young et al., 1998). Some reviews have noted that differences depended on reporting method. Staff typically report no change, whereas observation studies report fewer behaviours that challenge (Emerson & Hatton, 1996). Kozma et al. (2009) suggest observational methods may record more subtle behaviour changes than standardised questionnaires.

3.24 **Psychotropic medication:** Psychotropic medication is widely used to manage behaviours that challenge, despite questions about its efficacy (Matson & Neal, 2009). However, only one review (Kozma et al., 2009) examined its use, and findings were variable. Indications are that medication is more commonly used in community residences, as institutional settings tend to exercise more restrictive practices. However, more evidence is required.

3.25 **Exposure to crime and abuse:** Finally, a limited amount of research suggests that individuals with intellectual disabilities living in dispersed housing may be exposed to more verbal abuse and crime than those who are not living in the community, but that individuals supported in cluster housing or village communities are at lower risk (Kozma et al., 2009).

SUMMARY: IMPACT OF DEINSTITUTIONALISATION ON QUALITY OUTCOMES

3.26 The reviews summarised here demonstrate that, overall, when individuals with intellectual disability move from institutional to community settings they experience substantial improvements in many key life domains. There is strong evidence of improvements in adaptive behaviour, social relationships, community participation, and opportunities to exercise choice, self-determination, and satisfaction (personally and with residential supports). There are also improvements in overall quality of life, and greater satisfaction reported by family members, some of whom had been satisfied with institutional care and had resisted community living. In addition, there is strong evidence for increased engagement in community settings.

3.27 However, there are important limitations to these gains. Increases in adaptive behaviour and quality of life typically plateau after 1-2 years. Individuals' connectedness with family and friends is strongly mediated by their level of ability and behaviours that challenge. Their social networks are generally small, rarely extending beyond family or the support agency, and they may have little personal contact with members of their community. There is evidence of poorer health behaviours (relating to smoking, diet, activity), although some researchers construe this as the result of greater choice and self-determination, itself a quality outcome. There may be higher mortality rates among people with intellectual disabilities associated with modifiable care and lifestyle patterns. Inadequate accommodation and care planning, and delays in providing physical and mental health care, have been identified as potentially related factors.

3.28 A further limitation is that the large-scale quantitative studies included in these reviews have been criticised for relying on simplistic measures of inherently complex experiences. Studies examining social inclusion, for example, often simply count the number of times a person has left the house; studies have also been criticised for using proxy measures and excluding the voice of people with intellectual disabilities (Bigby & Fyffe, 2006).

3.29 A major limitation of these studies is that 'community living' encompasses many different community settings. As findings are pooled, it is not possible to identify variations in outcomes (Young et al., 1998), impeding attempts to understand which type of community settings provide the greatest benefits, and to identify which people living in the community do not experience positive outcomes (Bigby & Fyffe, 2006).

3.30 A related concern is that some comparisons have suggested that higher-quality institutions can produce outcomes as good as weaker community-based settings, undermining consensus on deinstitutionalisation and casting doubt on the financial investment required for community living (Mansell, 2006). This finding is, in part, related to the two highly influential factors noted in sections 3.3 and 3.4: individual characteristics and staff support. Compared to people with lower support needs, those with greater needs experience poorer outcomes wherever they live, are the last to leave institutional care, and are at greater risk of reinstitutionalisation (Emerson et al., 2000; Felce & Emerson, 2001; Felce, Lowe & Jones, 2000; Intagliata & Willer, 1982; Perry et al., 2000; Wing, 1989). Active staff support also has a strong influence on outcomes (Mansell, Beadle-Brown, MacDonald & Ashman, 2003). Collectively these findings suggest that once the social and physical environment are improved, individual characteristics and staff performance are the key determinants of quality outcomes in the community (Mansell, 2006).

3.31   In summary, deinstitutionalisation studies indicate that many outcomes improve for people with intellectual disabilities when moving to the community. The shift to community living is not of itself, however, sufficient (Mansell et al., 2010): 'deinstitutionalisation' entails more than closing institutions. It also involves developing high quality community services that can support individuals in new ways, including those with severe and profound disability (Bigby & Fyffe, 2006; Kozma et al., 2009; Mansell et al, 2010; Parlalis, 2011). Systemic changes in organisations, staff, and the community are required to achieve this (Bigby & Fyffe, 2006); these are addressed in Sections 9 and 10. First, however, we turn to the quality outcomes for individuals with disabilities in different types of community settings.

4. After Deinstitutionalisation: How Do Community Living Options Compare?

In some respects it may appear that the culture in these group homes resembles that of institutions.

(Bigby, Knox, Beadle-Brown, Clement & Mansell, 2012, p. 462)

4.1   The need for deinstitutionalisation continues after institutions have closed. Unfortunately, community settings can reproduce institutional cultures (Bigby et al., 2012; Felce & Emerson, 2001; Landesman, 1988; Mansell & Beadle Brown, 2009; Mansell et al., 2010; Sinson, 1993). Staff in community group homes have been found to engage in institutional practices, such as 'othering' people with intellectual disabilities; resisting active support, individualised activities, and community participation; and centring work practices on staff preferences, rather than those of supported people (Bigby et al., 2012). Furthermore, some campus-style community clusters bear similarities to large residential centres that were built on campus models (Mansell & Beadle-Brown, 2008).

4.2   Community-based settings vary considerably. Some support many people in one location; others are smaller and more dispersed; and standards in some poor community-based services can be lower than in better-run institutions. The variation in community-based services needs to be better understood, to ensure that benefits of community living are not dismissed on the basis of poor-quality settings (Mansell, Beadle-Brown & Clegg, 2004).

4.3   Some of the reviews summarised in Section 3 also compared findings from the less extensive 'post-deinstitutionalisation' literature. They report that autonomy, choice and skill acquisition can be supported more actively in smaller settings than in larger ones, and that gains in adaptive behaviour are more likely in smaller settings (Kozma et al., 2009; Walsh et al., 2010). Individuals in smaller community settings also report greater choice and self-determination (Walsh et al., 2010), although one review concluded this effect was driven by staff practices and empowerment rather than home location and size (Kozma et al., 2009).

4.4   The reviews concluded that, for social relationships and community activity, compared with people living in larger-scale community settings (e.g., group homes), people in supported living tended to have more friends outside the home, be more known to neighbours, and have more visitors (Kozma et al., 2009; Walsh et al., 2010). People with tenancy agreements had larger social networks (Walsh et al., 2010), but setting size was not related to loneliness (Kozma et al., 2009). Compared with staffed community housing, semi-independent or

supported living facilitated more community integration (Kozma et al., 2009). Employment status, however, was not associated with any community setting (Walsh et al., 2010). In general, smaller-scale settings in the community are associated with more skill acquisition and better social inclusion for people with intellectual disabilities.

4.5 Overall, however, relatively little research has been conducted, so it is difficult to conclude which community settings provide optimal outcomes. A further challenge is that multiple similar, terms are used in this field. Here, we clarify some of these before considering the few available studies in more detail.

DEFINITIONS OF DIFFERENT FORMS OF COMMUNITY LIVING

4.6 A primary distinction in community living options is between *clustered* and *dispersed* housing. We draw on Mansell and Beadle-Brown (2009) to define these concepts (Table 2). Clustered housing forms a clear separate unit, either in a segregated location or within the community. Dispersed housing consists of single dwellings scattered throughout the community and has been defined as "apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population" (Mansell & Beadle-Brown, 2009, p.10). Some examples are outlined in Table 2, though it should be noted that there may be considerable variations within each type of accommodation.

Table 2: Definitions of different forms of community living
(Mansell & Beadle-Brown, 2009)

Clustered housing includes:	
Campus settings	These are often in the grounds of former institutions; they are not located in the community and typically serve people with higher support needs.
Cluster housing or *community clusters*	Settings such as a cul-de-sac in a general residential community, where people with intellectual disabilities live in relatively small number of houses on the same site. Note that these terms are very similar to the more general term, 'clustered housing', which may cause confusion.
Village or 'intentional' communities	Volunteer support workers share their lives with people with intellectual disability (e.g. Camphill or L'Arche communities in Ireland and internationally), typically supporting people with milder intellectual disability
Dispersed housing includes:	
Community group homes	Groups of 3-8 people (possibly including those with high support needs) live in a house in the community with staff support according to their needs. This is probably the dominant form of community provision internationally (Mansell & Beadle-Brown, 2009) and is dominant in Ireland (Kelly, Kelly & O'Donohue, 2013).
Independent or *supported living*	People with disabilities rent or own their own home; they may choose to share with others. They have housing rights as other citizens do and receive staff support as a domiciliary service from a provider of their choice (Mansell & Beadle-Brown, 2009). Support is provided 'as required', and therefore ranges from minimal to fully staffed.

4.7   *Is it congregated?* Finally, it should be borne in mind that some community-based living arrangements may, if supporting large numbers of individuals, be classified as congregated. The definition of the Health Service Executive (2011) Working Group for the *Time To Move On From Congregated Settings* policy report in Ireland, for example, considers any setting supporting 10 or more people with intellectual disabilities (e.g. a large group home, or several houses in a cluster), even if it is located in the community, to be a congregated setting.

COMPARING CLUSTERED AND DISPERSED HOUSING

4.8   A small number of studies has compared clustered with dispersed housing. Clusters may be campus-based; community-based; or within village or intentional communities. The body of research, although small, appears to indicate that different forms of clustered housing are associated with different patterns of outcomes.

4.9   Emerson et al. (2000), in a seminal study funded by the UK Department of Health, compared costs and benefits experienced by individuals with intellectual disabilities in dispersed housing, NHS (National Health Service) campuses, and village communities. When findings were adjusted for level of ability and behaviours that challenge, dispersed housing cost 15% more than residential campus settings, and 20% more than village communities. However, further cost analysis based on matched samples revealed few statistically significant differences between services. In addition, dispersed housing and village communities were associated with significant benefits, compared with NHS campus settings.

4.10   Dispersed housing, which had better qualified and more senior staff, was associated with more personal choice, participation in community activities, and personal relationships. Village communities were associated with better activity planning, access to health checks, more routine day activities, and less likelihood of exposure to crime or verbal abuse (Emerson et al., 2000).

4.11   In another comparison of clustered and dispersed housing, Young (2006) compared suburban dispersed housing in Australia with campus housing (campuses of 7-8 detached and semi-detached houses on large parcels of land distinct from the community, similar to ordinary housing in suburban areas of Brisbane, providing 24-hour residential support to 12-25 people with intellectual disabilities). Individuals had significantly better outcomes in domains such as adaptive behaviour, domestic skills, vocational activity and choice in dispersed housing. There was no difference between settings in contact with family and friends.

4.12   Fahey, Walsh, Emerson and Guerin (2010), in a comparative follow up study of Irish services, examined quality outcomes from people supported in residential centres, intentional (village) communities and community group homes. This yielded a picture of varying benefits by setting type. In intentional communities, settings were smaller, and social distance was lower, but individuals had less choice and involvement than in community group homes and they lived further away from their family members than other comparative groups.

4.13   These findings reflect a companion paper to the Emerson study which reported that village communities and dispersed housing, compared with residential centres, were associated with specific patterns of benefits (Hallam et al., 2000). The authors recommended that a spectrum of residential options be offered, to address individuals' differing needs.

4.14   One subject of heated debate is whether *community-based* clusters (as distinct from *campus* clusters) are optimal. Relatively little research has been conducted on this topic (Young, 2006), but proponents argue that, compared to more dispersed housing options, clusters of

housing in the community provide a sense of community and better social relationships, and therefore a better quality of life, for people with intellectual disabilities.

4.15   Cummins and Lau (2003; 2004), for example, argue that social, rather than physical connectedness, improves quality of life in the community, and efforts to optimise outcomes for people with intellectual disabilities should focus on creating a sense of belonging. They conclude that community connectedness with others with intellectual disabilities is a desirable goal, that such relationships should not be devalued, and that clustered housing should prevail among the options available to people with intellectual disabilities. They also note the challenge of ideological prejudice against such community living arrangements.

4.16   Emerson (2004a, 2004b) is among those who believe that clusters are "segregationalist" and difficult to justify. In one study (2004a) he compared dispersed housing with several clustered housing types including campus clusters (three or more houses with an on-site day centre) and cluster housing (e.g., a cul-de-sac with three or more houses for people with intellectual disabilities). There was no evidence that these provided a "connected community". After adjusting for levels of need, Emerson concluded that individuals in clusters had poorer levels of support and quality of life compared with those in dispersed housing. Houses were larger and less staffed, and individuals experienced more staff turnover; more short-term residents; more restrictive practices (sedation and restraint); and fewer social and leisure activities.

4.17   Bigby (2004) notes that other studies, although not rigorous, appear to support Emerson's (2004a) findings that cluster housing produces less favourable outcomes on a number of dimensions. Bigby suggests, however, that the most pertinent questions that need to be asked are: why has a demand for cluster housing emerged; why has a strong push for alternatives to small group community living emerged; and why are deinstitutionalisation programmes moving towards larger scale congregated living rather than more individualised support and housing? Bigby notes that answers may lie in the fact that community group housing has often not delivered on quality promises, and parents in particular have felt their misgivings have not been heard, and have therefore searched for "better or perhaps least-worse" options (p. 204).

4.18   Mansell and Beadle-Brown (2009) conducted an extensive review of all research papers post 1990 which compared quality of life in clustered housing (village communities, residential campuses, or community-based clusters of houses) with dispersed community options. In total, 19 papers were sourced representing ten studies with 2,500 participants. These measured well-being, physical health, self-determination and service provision in 95 different domains, which were grouped into eight broad clusters. In five of these broad clusters – self-determination, personal development, social inclusion, material well-being and rights, no studies reported benefits of clustered settings. For interpersonal relations, emotional, and physical well-being, clustered settings had some advantages.

4.19   Mansell and Beadle-Brown (2009) caution however that where the above domains clustered settings showed advantages, this applied only to village communities. They conclude that these communities therefore comprise an important portion of the spectrum of supports but, given that they typically support people with higher levels of ability and rely on volunteers, they are unlikely to represent anything more than a niche option in the living arrangement options for people with intellectual disabilities. At the same time it should be noted that proponents of active support argue that village communities, as a form of congregated setting, are not settings in which it is possible to implement active support (Mansell & Beadle-Brown, 2012). This represents a substantial limitation of this form of support.

4.20   Overall, therefore, the weight of a relatively small body of evidence indicates better outcomes for dispersed housing in the community, compared to campus clusters and community-based clusters. However there are some benefits associated with village communities and commentators suggest these therefore offer quality support, albeit as a minority option.

4.21   Community group housing – which is the most common form of community living in Ireland – has often not delivered on quality promises (Bigby, 2004). However, comparisons with other forms of dispersed housing are relatively rare (Mansell, 2006). Some studies have compared dispersed housing with semi-independent living, matching participants for adaptive behaviour and behaviours that challenge (Felce et al., 2008; Stancliffe & Keane, 2000). Others have compared various community-based options with the family home (Stainton, Brown, Crawford, Hole, & Charles, 2011), or have looked exclusively at the outcomes living in community group housing (Bigby et al., 2012; Clement & Bigby, 2010).

4.22   Stancliffe and Keane (2000) compared outcomes for people with moderate or low support needs in community group homes with matched participants in semi-independent living (defined as 1-4 people living with part-time paid support and no night time staffing). They found no differences on 24 of 29 indicators such as use of mainstream community facilities, quality of life satisfaction, social belonging, contact with friends and family, safety at home and away, money management, and health. Where domains differed, semi-independent living was better for: social satisfaction, empowerment, frequency of community use, number of community places used without staff support, and domestic participation. Lower levels of staff support and lower costs in semi-independent living did not translate into poorer outcomes (Stancliffe & Keane 2000). On the contrary, the authors propose that the fact that staff are not always present may encourage people supported in independent living to acquire skills.

4.23   Felce et al. (2008) also matched pairs of individuals with relatively low support needs in fully staffed group housing with those in semi-independent living and similarly found no differences on most indicators. However, they found that participants in fully staffed houses had better outcomes for money management and health, in contrast to Stancliffe and Keane (2000). The authors also reported that people in semi-independent living had greater choice and, as Stancliffe and Keane reported, undertook more community activities without staff support. As costs of semi-independent living were found to be lower than of fully staffed community group homes, Felce et al. (2008) concluded that semi-independent living could offer multiple advantages, as long as health and financial matters were carefully addressed.

4.24   More recently, Stainton et al. (2011) compared quality outcomes for 852 individuals with intellectual disability living in four types of community-based living. Two provided more informal support: independent living (defined as receiving supported living services) and the family home; and two provided more formal supports: group homes and host families (where people with disabilities live with non-relatives who are paid to provide support). Where the support was more informal (independent living or in the family home), supported individuals were found to have greater choice and control. Where support was more formal (group homes and host families), access to services and crisis support, respect from staff, health and safety issues and community connectedness were greater.

4.25   Stainton et al. (2011) note that less service access in the more informal settings (family or independent living) may reflect lower levels of need. The authors note, however, that individuals were asked about access to 'needed services'. They suggest that the findings

highlight the need for vigilance to ensure that appropriate supports are available across all living options. They conclude that the data suggest that services promoting independent living may have failed to appropriately reorient their supports.

4.26   Under a policy of 'personalisation' pioneered in the UK, individuals with disabilities were offered considerable control over the support they received (Manthorpe, Moriarty & Cornes, 2011). Pioneered by the 'In Control' organisation, individuals receiving social care were supported to become involved in their own assessment for services, take control of a personal budget to fund their support, and exercise choice and control over their supports (Poll, Duffy, Hatton, Sanderson & Routledge, 2006). An evaluation found that 196 individuals, most of whom had intellectual disabilities, reported gains in quality of life, community engagement, choice, control, dignity and well-being among others. Movement towards consumer-directed support can be seen in the rapid increase in individuals taking control of their personal budgets, from 60 in 2006, to over 30,000 in 75 local authorities in 2009 (Tyson et al, 2010).

4.27   A small number of qualitative studies has explored staffing practices in poorly performing community group homes. In Australia, Bigby et al. (2012) found a staff clique dominated the group home culture. They were opposed to national policies, to the values of the organisation, and to change overall, and many examples of 'othering' were found in their language and practice, suggesting an 'us and them' attitude towards people with intellectual disabilities (e.g. separate toilets and crockery). Work practices were organised around staff preferences, not those of supported people. Staff perceived their role as doing 'for', not 'with'; and they resisted change. Similarly, in another low-performing group home, when compared with homes with similar resources and demographics but better quality of life for supported people, staff were found to have task- rather than person-orientated styles (Gillett & Stenfert-Kroese, 2003).

4.28   In a detailed ethnographic account of the lives of people with severe and profound intellectual disability in group homes in Victoria, Australia, Clement and Bigby (2010) found frequent poor outcomes, weak implementation, and ambiguity regarding policy goals of choice, control, decision-making, independence, friendship, meaningful engagement, 'quality of life', reciprocity, rights, self-determination and building inclusive communities. They also found significant gaps between what staff should do and what was actually practised, particularly in relation to "facilitating relationships between people with intellectual disabilities and others; discovering people's needs and wants; communicating with people with severe and profound disabilities; and having medium to long-term planning" (p. 250). The authors noted that many skills required for such support are beyond the training received by most direct care staff. Moreover, formal supervision and planned formal staff appraisal were lacking. Clement and Bigby (2010) recommend that "broad social policy goals [be] translated into clear statements that detail what each goal means for people with severe and profound disabilities. These specific statements should be aligned with the overarching goal of 'an ordinary life' " (p. 261).

4.29   The impact of type of community service provider on quality outcomes (voluntary, private or state) has rarely been examined. One UK study, examining outcomes for 254 adults with intellectual disabilities living in settings of six persons or fewer, reported marked differences in staffing levels: state health authorities and voluntary sectors had highest staffing levels (Perry, Lowe, Felce & Jones, 2000). The authors interpret this as reflecting the higher support needs of people in these settings compared with the people living in state, local authority or privately provided dwellings. The health authority and voluntary providers were also distinguished by staff working practices such as individual planning procedures, staff training, and practices for supporting individuals. While these differences suggest that organisational factors are influential, the authors note that difference in working practices could not be inferred to reflect differences in quality outcomes supported individuals (Perry et al., 2000).

4.30   Finally, it should be noted that many researchers advocate strongly for smaller settings, as do some self-advocates (Felce & Emerson, 2001; Parish, 2005), but family members often prefer clustered settings, sometimes expressing exclusively positive views about them (Bigby, 2004; Doody, 2011). Family members appear to have the sense that their relative will be safer in clustered settings. Views of family members and people with intellectual disabilities are considered further in Section 6.

SUMMARY: DISPERSED COMMUNITY LIVING OPTIONS

4.31   On most indicators, dispersed housing provides outcomes as good as or better than clustered housing, with the exception of village communities in some cases. The weight of evidence, although the body is small, does not support the views that clustered housing delivers a lower cost version of the same quality of life, or that it promotes social connectedness.

4.32   The form of dispersed housing that currently predominates, the community group home, has been found to be less than optimal. Resistance to new policies and misaligned working practices contribute to under-performance in some group homes. Comparative studies between independent living and community group homes have found few differences. Self-directed supports, where individuals with disabilities take control of their supports, are typically not included in these comparative studies. The type of provider (family, private or state) has been linked to different benefits, with health authorities and voluntary agencies providing specific staff-related benefits, such as higher staff ratios and better working practices.

5. The Issue of Cost

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.

(Mansell et al., 2007; p.97)

5.1   The cost of disability service provision in Ireland is substantial. The Value for Money and Policy Review of Disability Services (Department of Health, 2012) revealed the full annual cost of disability services in Ireland in 2009 was €1.859 billion. An estimated three-quarters of this budget was used to deliver services specifically to people with intellectual disabilities; up to 84% of these costs were staff salaries. These figures are estimates as, at the time of publication, the authors commented that *'the HSE does not maintain sufficient information on sources of funding for voluntary providers because it does not systematically collect data on funding sources or reconcile these to annual accounts'* (Department of Health, 2012; p.47).

5.2   The Value for Money and Policy Review estimated that expenditure on residential services for people with intellectual disability totalled €371 million euro in 2009. Most of this expenditure was spent on delivering seven day a week residential supports, services which are increasingly in demand. At the time of publication expenditure on residential provision was evenly balanced between institutional and community-based services. Although the state allocation for a residential place was estimated at €70,000 per annum, the Value for Money

and Policy Review noted that actual expenditure on residential places varied markedly, ranging from €35,086 to €139,739, depending on individual need.

5.3   These national figures illustrate the scale of the challenge facing Ireland in redistributing the funds currently spent on congregated settings. As disability services transform from a congregated model of service provision to more personalised services, the allocation of funding, most particularly residential funding, will become more fragmented. Below, we outline some of the key research evidence from studies which have explored the impact on expenditure when reconfiguring service delivery to more individualised options. First, however, we outline some important issues which should be considered when interpreting the findings from this body of research.

ISSUES FOR CONSIDERATION WHEN INTERPRETING COST DATA

5.4   First, research examining the relationship between the support needs of people with intellectual disabilities and costs has consistently reported greater costs for those with higher support needs (Hallam et al., 2002; Knapp et al., 2005; Mansell et al. 2007). As Mansell (2010) observed *'it is self-evident that services for adults with profound intellectual and multiple disabilities will be more expensive than those for people with less severe disabilities: the major element of costs is personal assistance and these people will need personal assistance almost all of the time if they are to have a good quality of life'* (Mansell 2010; p.14).

5.5   Moreover, *'in a good care system, the costs of supporting people with substantial disabilities are usually high, wherever those people live'* (Mansell et al., 2007; p.97). Out of area placements, for example, supporting people with significant needs are typically expensive (Beadle-Brown et al., 2005; Pritchard and Roy, 2006; Perry et al, 2007) although as this association is mediated by staffing levels, some out of areas placements may be less expensive than higher staffed local services (McGill and Poynter, 2012; Perry et al 2013).

5.6   A second issue to note is that, when comparing the costs of different living arrangements, the association between level of ability and costs must be considered, so that comparisons are made on a 'like-for-like' basis. Certain living arrangements are more likely to be availed of by individuals with specific types of disability; for example, for historical reasons people with more severe levels of disability are more likely to be supported in more congregated settings (Mansell et al., 2007). A simple comparison of people supported in larger and smaller settings may therefore erroneously suggest that larger settings are inherently more expensive. In this situation, level of ability is termed a 'confounding' issue which must be controlled for, usually by statistical analysis (Mansell et al., 2007).

5.7   Third, a significant and common misconception when comparing costs of different living arrangements is the optics of 'economies of scale'. The economies of scale argument is an economically compelling argument, which suggests that the per person cost of support services decreases as the number of persons supported increases. It suggests that there is a powerful financial incentive to retain large scale congregated living arrangements (Mansell et al., 2007). This argument, however, falls short on a number of issues:

- Economies of scale fail 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"* (Mansell et al., 2007; p.43). If the quality of service provision in institutions were to approach anything close to that of community-based services, for example by enhancing the physical environment or staffing levels, the level of investment required would quickly diminish any apparent cost savings. Even if such

investment were made in enhancing the institutional environment, quality outcomes would still remain below those reported within community settings. It is therefore *'essential to take account of the consistently superior developmental and lifestyle outcomes following movement from institutional to community settings'* when considering cost data (Stancliffe, Lakin, Shea, Prouty & Coucouvanis, 2005, p.289)

- Contrary to expectation, the available evidence identifies only one situation where economies of scale play out as expected; that of very small settings where staff presence is required on a full-time basis (Felce & Emerson, 2005). In these settings, the fixed salary costs of round-the-clock staffing cannot be reduced if fewer people are supported. As Lakin & Stancliffe (2005) note: *'the available evidence suggests that economies of scale play little or no role in the cost of many community residential services and only have a significant influence in very small settings with continuous paid staff'* (p.324).

5.8 A final issue to be considered when examining cost studies is that costs are typically restricted to the direct costs incurred by a leading service provider agency, most of which are direct support staff costs. Other costs, rarely examined in research studies, include the costs incurred by other service providers (whether mainstream or disability services), the 'hidden cost' of unpaid caregivers such as family members, and the 'intangible cost' of caregiving such as stress related illness (Mansell et al., 2007). Cost comparison studies are thus likely to substantially underestimate the full costs of support.

5.9 The issues of 'like-for-like' comparisons, economies of scale and a reliance on direct support staff costs are important to bear in mind when interpreting the findings of cost studies. Comparative studies of cost, in particular, are complex and easily misunderstood (Health Service Executive, 2011). We now present some of the key cost comparisons between institutional and community services, transition costs during deinstitutionalisation, cost comparisons among community services, and costs associated with self-directed services.

COMPARING INSTITUTIONAL AND COMMUNITY-BASED COSTS

5.10 Evidence from the US has consistently reported higher costs for institutional provision than for community-based options. Research studies examining costs and quality outcomes simultaneously have reported community settings to be less expensive than state institutional services by up to 27% (Stancliffe et al., 2005).

5.11 This cost difference is even more marked when examining the US annual audit of deinstitutionalisation trends since 1977 (Larson, Salmi, Smith, Anderson & Hewitt, 2013). The most recent audit found considerable disparity in per person costs between those supported in large ICF-ID facilities (Intermediary Care Facilities for People with Intellectual Disabilities, of which 53% support 16 or more people) and those supported in more personalised, community-based services (Medicaid Home and Community Based Services; HCBS waivers). The average 2011 per person annual cost for a person supported in an ICF-ID was $148,146, compared to $45,294 for those supported through HCBS community services was. It should be noted however that those supported under HCBS waivers include residential supports for individuals who remain in the family home.

5.12 Several factors contribute to the lower cost observed in US community settings. A major contributor is higher staff costs in state institutions, where salaries were estimated to be 26% higher than for community services. Another contributor is that many state institutions operate below capacity, supporting considerably fewer people than they were originally designed for – a phenomenon termed 'dis-economies of reduced scale'. Finally, US state institutions have

mandatory requirements to meet specific regulatory standards that are not required of smaller, community dwellings (Stancliffe et al., 2005).

5.13   A similar pattern of findings was reported by Chou, Lin, Pu, Lee & Chang (2008) for costs and quality outcomes in Taiwan. Three models of living arrangement were evaluated: institutional care (supporting over 100 people), community group homes (supporting 10-40 people) and the newest model of support, small community dwellings where fewer than 6 people are supported. As with previous research, quality outcomes were enhanced in smaller, community-based settings. Similarly to US findings, institutional costs were higher than for community services. Average monthly costs were reported as $28,067 in institutions, $20,920 in community group homes and $17,638 in the smaller community-based settings. The authors conclude that smaller dwellings provided better outcomes at lower cost.

5.14   Recent Irish data is available from a nationwide evaluation of demonstration projects supporting people with disabilities to move from congregated to more personalised services (McConkey, Bunting, Ferry, Garcia-Iriarte, & Stevens, 2013). The evaluation involved 197 individuals, of whom 116 had an intellectual disability. Cost data were gathered over three time periods over two years (spanning October 2011 to May 2013). Median monthly costs of direct support were determined for individuals who had moved to new supports, and for those who were still awaiting a move from their original accommodation.

5.15   The highest cost, €10,348 per month, was recorded for individuals who remained in congregated settings through the three data collection points. The next highest was recorded for individuals who moved from congregated settings to community group homes, a median monthly cost of €7,365. Those moving from congregated to personalised supports reported the largest decline in costs, from a median monthly cost of €7,365 to €2,308. Finally, the lowest staffing costs were reported for those living with family and those living in personalised living arrangements and who remained there for the duration of the study, estimated at €2,204 and €1,710 respectively. These costs reveal a pattern similar to those observed above, where more personalised and community-based living arrangements are associated with lower cost.

5.16   Findings from the UK contrast significantly with those reported above. UK studies have repeatedly found community services to be more expensive than congregated settings (Felce, 1994, Felce, Lowe, Beecham & Hallam, 2000; Hatton, Emerson, Robertson, Henderson & Cooper, 1995; Knapp et al, 1992). A seminal study comparing NHS residential campus settings, village communities and dispersed housing was conducted by Prof Eric Emerson and colleagues (presented in Section 4.9). In addition to examining quality outcomes in these settings, the study also examined their relative costs (Emerson et al., 2000; Hallam et al., 2002). Dispersed housing was 15% more expensive than NHS residential campus settings and 20% more expensive than village communities. Emerson and colleagues argue that the quality benefits associated with dispersed housing justify higher costs than NHS residential campus settings which offered significantly poorer quality. The cost differential between dispersed and village communities is described as being of 'clear policy relevance', although marginally lower quality outcomes were reported in village communities.

5.17   UK longitudinal research suggests that the disparity in costs may moderate over time. A follow-up study of the UK demonstration programme *Care in the Community* examined costs for people with intellectual disabilities 12 years after they moved from hospital settings to the community. Community costs remained higher than hospital –based costs, but the difference narrowed over time. The authors observed that the decline in community costs is counter-intuitive, as individuals would be expected to require greater levels of support as they age. One explanation may be the restricted budgets of local authorities when commissioning

supports, a pattern which the authors noted had "very disturbing consequences for residents" (Hallam et al., 2006, p.305).

5.18   The differing international findings in cost studies comparing institutional and community-based services may seem confusing, but they raise an important insight into underlying drivers of cost in residential services. The size of a setting is not of itself, as perhaps may be expected, a key factor. Rather, other factors such as the model of support, the requirement to meet quality standards, and differences in pay scales all contribute to mediate cost (Health Service Executive, 2011; Stancliffe et al., 2005). As noted above, personal characteristics of the person such as level of ability are also a major contributing factor to cost.

5.19   Notwithstanding the higher cost of community-based living arrangements observed in the UK, the available evidence suggests that *'once the comparison is made on the basis of comparable needs of residents and comparable quality of care there is no evidence that community-based living arrangements are inherently more costly than institutions'* (Mansell et al., 2007). That is, community-based living may be more expensive than poorer quality institutional care, but it is more cost-effective as it offers better quality outcomes for people with disabilities.

COSTS DURING TRANSITION FROM INSTITUTIONAL TO COMMUNITY SUPPORTS

5.20   The relationship between costs and quality outcomes during transitions from institutional to community services was comprehensively reviewed as part of the DECLOC report (Deinstitutionalisation and Community Living Outcomes and Costs; Mansell et al., 2007). Patterns of transitional costs were identified, drawing on extensive evaluations of the transition of mental health services to the community (Knapp, Chisholm, Astin, Lelliott & Audini, 1997). The first cohort of people who move from institutional provision are typically those with lower support needs. As people with higher support needs move in due course, the average cost in the community rises, because those with higher support needs have higher support costs wherever they are supported. Over time, those remaining in institutional care are people with very significant support needs, whose support costs are substantial. As a consequence, the average cost in an institution is likely to rise during the process towards closure (Mansell et al., 2007).

5.21   Mansell and colleagues stress that policy makers embarking on a deinstitutionalisation programme must be familiar with these trends in costs. As the process of deinstitutionalisation gains momentum, increases should be expected both in the average cost of supporting a person in the community and in the average cost of supporting a person in an institution. The authors caution that cost predictions of deinstitutionalisation, frequently based on the average costs of supporting people in the community, are likely to under-estimate the true costs required to achieve community living for people across the full spectrum of support needs.

5.22   Stancliffe et al. (2005) recommend that institutional closures be undertaken swiftly, as the process of downsizing involves significant operational costs, irrespective of the declining number of residents. These authors argue that providers may find themselves paying *'inordinately high costs for inferior outcomes"* on the basis that costs become stalled within institutions when they could be diverted to community services of higher quality.

5.23   Whatever the pace of transfer, funding new community services and keeping an institution running until full closure, involves incurring double costs, known as 'hump costs'. Therefore, injections of investment will *'almost always be needed in the short-term*' (Mansell et al., 2007, p. 97). In time, funds may be recouped by selling the institutional property and lands, which

can be transferred to community services. In the interim, Mansell et al. (2007) propose that attempting to reconfigure services cost-neutrally or with cost savings *'could result in many people being denied adequate care, or moved into substandard settings with little support'* (p. 79).

5.24   Emerson et al. (2001) compared costs across three types of dispersed community settings: large group homes supporting 4-6 people, small group homes supporting 1-3 people and supported living. No differences were found between costs of these forms of dispersed housing. The authors note that supported living provided distinct benefits, for the same cost as the other options, in terms of resident choice and community participation.

5.25   A number of international studies have reported lower costs in smaller and more personalised community settings. A follow-up study of individuals resettled from NHS hospitals in the UK (cited in 5.16 above) examined the costs of supports 12 years after resettlement. Adjusting for level of ability, those in residential or nursing homes incurred the highest costs, followed by those supported in community group homes. Costs were lowest for individuals in 'minimal support' arrangements (unstaffed or independent living options) and hostels (Hallam et al., 2006).

5.26   Substantially higher costs have been reported for fully staffed community group homes compared with more flexible living arrangements. In Australia, group homes were found to be five times more expensive than semi-independent living (households of 1-5 people who had regular part-time staff support), with annual costs of AUD 51,853 and AUD 10,056 respectively (Stancliffe, 2005; Stancliffe & Keane, 2000). Similarly, in the UK, the cost of care for people supported in fully staffed houses was almost three times higher than the cost of semi-independent living (no paid staff for at least 28 waking hours per week). Weekly costs were US $1,539 and US $542.10 respectively (Felce, Jones, Lowe & Perry, 2003).

5.27   Following adjustment for level of ability, these cost comparisons of community options reveal, perhaps unsurprisingly, that living arrangements with lower staffing levels are less costly. In combination with the evidence on quality outcomes, these studies suggest that people who are currently living in group homes *"may achieve similar or better lifestyle outcomes, at lower cost, by living semi-independently. These individuals should be given the opportunity and support to live semi-independently if they choose"* (Stancliffe, 2005, p.147).

5.28   The move towards more personalised services (see Section 4.26) has provided opportunities for people with disabilities to take control of not only their own services ('self-direct') but also of the budget that funds their supports. By definition, this option is likely to see disability funding dispersed across more services, to include those from mainstream health, housing and social care providers. This fragmentation of funding can cause challenges. Attempts to streamline financial streams include brokerage services where agencies provide an administration function to support individuals navigate disparate funding streams. In the UK, local authority care managers are charged with providing these services (National Disability Authority, 2011a).

5.29 Personalised budgets, defined as 'an upfront allocation of social care resources based on an assessment of the individual's need for non-residential social care' are deemed to provide greater equity as funding allocations are based on individual support needs (Department of Health [UK] 2009). The popularity of this model can be seen in England where almost 450,000 individuals in receipt of social care in 2012 chose to receive a personal budget; equating to 53% of all those eligible for personal budgets (ADASS, 2012).

5.30 Evaluative data on personal budgets has been described as 'patchy' and confounded by the fact that the introduction of such a new scheme is likely to identify unmet needs, consequently increasing both demand and cost (Carr & Robbins, 2009). Early evaluations estimated that self-directed costs were 10% less costly than traditional services (Leadbeater, Barlett & Gallagher, 2008; Hatton et al., 2008). Similarly, savings reported from demonstration projects in the United States pioneered by the Robert Wood Johnson Foundation ranged 12% to 15% (Conroy & Yuskauskas, 1996, cited in Stancliffe & Lakin, 2004). More recently a review by the Productivity Commission of Australia (2011) concluded that *"there is enough evidence from diverse sources to suggest that self-directed funding is likely to be less costly than alternative service models"* (Productivity Commission, 2011, Appendix E, p.19).

5.31 Caution is required, however, as some personal budget systems have become 'unsustainable'. In the Netherlands, the number of individuals receiving personal budgets increased 10-fold in 8 years (13,000 in 2002 to 130,000 in 2010), with spending for these individuals increasing on average 23% per year, far greater than increases for individuals receiving support through more traditional routes. The Dutch Ministry of Health concluded that the increases reflect the fact that individuals such as children and adolescents previously receiving informal family support were now claiming personal budgets (van Ginneken, Groenewegen, & McKee, 2012).

5.32 The introduction of personal budgets is in its infancy in many jurisdictions. The evidence to date suggests that although costs for this form of support are typically lower than for traditional supports, the creation of a new finance system will likely identify unmet need and consequently may incur substantial cost.

THE ISSUE OF COST: SUMMARY

5.33 In conclusion, the evidence on relative costs of different living arrangements is limited, and in some cases emerging. General trends in most jurisdictions suggest that community living options are less expensive than institutional care. Moreover, smaller community-based options with less staffing are typically the least expensive. Newer financing models such as self-directed supports are generally less expensive than traditional services, but are likely to create a new demand for support services. Foremost in this evidence are the findings that community options, even if more expensive than institutionalised models, provide better quality outcomes on a like-for-like basis.

6. Stakeholder Views of Community Living: People with Intellectual Disabilities and their Families

This isn't the place for me. My heart's not here. If I got the chance, I'd love to have a flat, to have my independence back.

(McGlaughlin, Gorfen & Saul, 2004, p.719)

6.1   The views of people with intellectual disabilities themselves on deinstitutionalisation and community living are clearly paramount. Views of family members such as parents and siblings with primary roles in caregiving and advocacy should also be considered. There are, however, relatively few studies exploring these perspectives.

VIEWS OF PEOPLE WITH INTELLECTUAL DISABILITIES

6.2   In general, there has been little consultation and engagement with people with intellectual disabilities regarding living arrangements (McConkey, Sowney, Milligan & Barr, 2004). Research that has explored these views is typically qualitative, involving interviews or focus groups (McVilley 1995; Gregory, Robertson, Kessissoglou, Emerson & Hatton, 2001).

6.3   Individuals with intellectual disability who remain in the family home into adulthood are reported to be happier, but lonelier than those who move to other options (O'Rourke, Grey, Fuller & McClean, 2004). Many of those living in the family home express a preference for more independent living (McGlaughlin, Gorfin & Saul, 2004), particularly if younger (Bowey & McGlaughlin, 2005). However, many professionals and family caregivers favour more congregated settings, e.g., residential centres and nursing homes (McConkey et al., 2004).

6.4   Individuals who move to residential services typically report high levels of satisfaction with their supports, a phenomenon termed 'the gratitude factor' (Gregory et al., 2001). Concerns that acquiescence may explain individuals' high satisfaction with services were explored with 93 triads, each with an individual with an intellectual disability, a family member and a staff member (Schwartz & Rabinovitz, 2013). Staff reported the greatest satisfaction with residential supports; individuals with intellectual disabilities reported the least. Staff ratings were particularly high where individuals had low scores on behaviours that challenge, worked in inclusive employment settings, and rented an apartment. The authors suggest this may reflect staff expectations that more normalised environments are more satisfactory, and individuals' expectations that they are not afforded levels of choice and control enjoyed by other people who live independently (Schwartz & Rabinovitz, 2013).

6.5   McConkey et al. (2004), in a qualitative study of 180 persons aged 22 to 63 years with mild to moderate levels of disability, similarly reported that most were satisfied with their current residential supports; indeed the authors note participants may have been reluctant to criticise their current arrangements. Group homes and supported living options were preferred, although disadvantages of community living included harassment, noise, disagreements among housemates and some aspects of the physical environment. Residential care homes, typically supporting up to 20 individuals, were thought to have some social advantages, but the general view of this form of support was negative.

6.6   Some research has specifically examined the satisfaction of people with intellectual disabilities in village communities. Semi-structured interviews with 96 adults found that satisfaction was moderately higher in village community settings (self-contained communities with living units in close proximity to a central day facility) than in dispersed community housing. Higher satisfaction levels however related to just one of seven life domains: friendships and relationships (Gregory et al., 2001). Similarly, high satisfaction with Camphilll village communities was reported in a small study of 15 individuals in a campus setting supporting 300 members in over 30 dwellings. The authors note that life in intentional communities may not appeal to all (Randell & Cumella, 2009).

6.7   Satisfaction levels have also been explored with older adults. In a large interview study of 92 individuals with intellectual disabilities aged 40 years or over, they were satisfied with the physical environment, staff support, and available activities. Dissatisfaction was dominated by staffing issues including staff shortages, expressions of impatience by staff, and staff practices deemed to restrict independence (O'Rourke et al., 2004).

6.8   The qualities that define good staff support were explored in a small qualitative study of seven individuals receiving residential services and seven managers. Stakeholders' views of desirable staff traits differed: individuals with intellectual disability prioritised interpersonal skills and managers prioritised staff practical skills. Individuals with intellectual disabilities particularly valued staff who gave active support, rather than completing tasks on their behalf (Dodevska & Vassos, 2013).

6.9   Underpinning much of this research is the finding that individuals with intellectual disabilities regularly report limited or no choice in their living arrangements (McGlaughlin et al., 2004; Miller, Cooper, Cook & Petch, 2008; Stancliffe et al., 2011) and difficult relationships with house-mates (Miller et al., 2008). People with disabilities have described feeling equally disempowered about possible residential moves in the future (Gorfin & McGlaughlin, 2004).

6.10   In combination, these findings suggest that satisfaction levels are typically high, wherever individuals with disabilities live. This should be interpreted with caution, as it may reflect an acquiescence bias. Preferences differ, with some individuals seeking more independent living options, while others wishing for non-community based options. Many, however, experience a lack of choice about where and with whom they live.

VIEWS OF FAMILIES

6.11   Family members of people with intellectual disabilities play a key role in decisions about living arrangements (Nieboer, Pijpers, & Strating 2011). As deinstitutionalisation has an inclusive impetus, family opposition may seem counter-intuitive. Yet some families have been reluctant to co-operate with community transfer programmes, and have at times advocated and even litigated for institutions to be kept open (Nieboer et al., 2011; Parish, 2005).

6.12   The views of family members should be placed in the context of their caregiving role. Their quality of life is affected both positively and negatively when supporting a family member with an intellectual disability. Parents in particular report that they benefit from their enabling role when they observe that their support has facilitated their child to establish relationships and engage in social activities. However, caregiving may also diminish quality of life by restricting social relationships, employment prospects and family finances (Yoong & Koritsas, 2013).

6.13   It is also important to recognise that for many family members, a decision to relinquish the care of a family member to a disability service provider may be precipitated by difficulties such

as behaviours that challenge, poor coping, lack of support, chronic financial concerns, or caregiver distress (Nankervis, Rosewaren & Vassos, 2011). Evidence suggests that although family members are generally satisfied with the residential supports provided to their relative, some report guilt and worry that caregiving has been placed elsewhere (Werner, Edwards & Baum, 2009). These are just some of the issues families grapple with as they negotiate service provision for their family member.

6.14   Family opposition to deinstitutionalisation is often based on fear that supports in community-based settings will be insufficient (Parish, 2005; Tossebro & Lundeby, 2006; Young 2006). However, evidence suggests that, in time, they typically express a preference for community options (Ericsson, 2000; Tuvesson, 1992; Tuvesson & Ericsson, 1995, cited in Ericsson, 2000; Tuvesson & Ericsson, 1996). Opportunities for family members to meet others who have experienced a move from institutional to community services are pivotal in addressing concerns (Parish, 2005). In a five year follow up of 68 individuals moving from long-stay hospitals to residential nursing homes in Northern Ireland, for example, family members reported increased satisfaction with staffing and the physical environment, most notably a more homely atmosphere where people had their own bedrooms. However, they were dissatisfied with the congregated nature of some of these facilities (McConkey, McConaghie, Mezza, & Wilson, 2003).

6.15   Future caregiving preferences were explored in an extensive qualitative study of 387 caregivers (pooling four studies) in Northern Ireland. Most expressed a preference for their relative with intellectual disability to continue to be supported in the family home (McConkey, McConaghie, Barr & Roberts, 2006). Where a service-provider living arrangement was required, these caregivers cited residential or nursing homes as the preferred option, followed by living with support in the individual's own home or in a home for small groups of people. These findings were age dependent: younger caregivers proposed more independent living. Of particular note in this study was the finding that only a minority of caregivers had made any plans for future living arrangements outside the family home (McConkey et al., 2006).

6.16   As a general trend, family members hold favourable views of clustered settings. Doody (2011), for example, conducted seven interviews in Ireland with family members of people with severe or profound intellectual disability, aged 34 to 74 years, who had moved to a campus-based cluster of bungalows after 16 to 34 years in a psychiatric institution. Family members reported extremely high satisfaction with their relatives' gains in independence, improved physical environment, their own greater role in shared care for their relative, and with supports provided by the intellectual disability nursing staff supporting their relative.

6.17   It is possible that highly positive feedback of some family members may, in part, reflect a reluctance to criticise the service their relative receives, similar to the 'gratitude factor' observed among individuals with intellectual disabilities. Participatory research conducted throughout Ireland, where family members acted as participants and co-researchers, found that "families felt they should be grateful for what they received from services" (p. 129), with some concerned that complaining would be perceived as 'rocking the boat' and lead to negative effects on their family member (Chadwick et al., 2013). These authors suggest that reluctance to criticise may reflect a "Roman Catholic ideology" underlying many voluntary sector services in Ireland.

6.18   Family members in this participatory research project called for more open, ongoing communication with service providers. Although some services were responsive to families' changing needs, others, particularly respite, home-based and therapeutic services, were often only provided when families were at 'breaking point'. Families reported feeling uninformed about family members' support needs, eligibility and entitlements. Many accessed information

by chance from informal contacts and felt that service providers hid information. Overall, families felt the needs of people with intellectual disabilities were ignored and that social attitudes were reflected in the lack of funding and government failure to implement policies (Chadwick et al., 2013).

6.19   Managing for the future care of a family member when the main caregiver withdraws from this role is a sensitive and difficult time. Recent gains in life expectancy by individuals with intellectual disability, who are now more likely to outlive their parents, have made this a more prevalent concern (Ansello & Janicki, 2000). Older parents, in particular, report many issues relating to future placements including the financial impact of securing a service, a perceived lack of empathy by some providers, and their own feelings of uncertainty about future provision for their family member (Weeks, Nilsson, Bryanton & Kozma, 2009).

6.20   Some family members are faced with the option of out of area hospital placements. Bonell, Ali, Hall, Chinn and Patkas (2011), for example, interviewed 16 family members whose relatives were currently in out of area psychiatric hospitals. Families outlined a considerable impact on their own well-being, including shame about their relative's behaviours which contributed to the admission, and fear about their relative's safety. The challenges of supporting a relative in acute and typically geographically distant settings, combined with the behaviours that preceded the admission, may be so overwhelming that they damage families' relationships permanently.

6.21   Overall, there is limited evidence for the family perspective. Although family members may initially fear deinstitutionalisation, this may diminish in time, particularly if they can meet other families who have experienced deinstitutionalisation. Preferences for living arrangements vary, but the family home and clustered arrangements emerge in a number of studies. These findings should be in the context of the sometimes challenging yet rewarding caregiving role of family members. For some, negotiations with disability providers are stressful and intimidating, a possible contributing factor to the reluctance by some for timely planning of residential living arrangements for their family member. The decision to relinquish the care of a family member is often stressful. The perception of families that they are uninformed and unsupported by service providers suggests there is room for improvement in this relationship.

SUMMARY: VIEWS OF PEOPLE WITH INTELLECTUAL DISABILITIES AND FAMILIES

6.22   A limited body of evidence, mostly qualitative and much of it conducted in Ireland, documents the views of people with intellectual disabilities and family members towards residential living arrangements. A number of commonalities emerge. Highly favourable satisfaction levels reported by both groups may, in part, reflect response acquiescence, and they may fear the withdrawal of a service if they criticise it openly. Both groups express some preference for remaining in the family home, and for clustered type settings, notably village communities. Finally, they report being disempowered by service providers. People with intellectual disabilities report a lack of consultation about where and with whom they live, and family members report feeling disempowered by poor information from disability service providers.

7. Supporting Life in the Community (I): Those with Higher Support Needs

Where children, young people and adults need specialist support, the default position should be to put this support into the person's home through specialist community teams and services, including crisis support.

(Department of Health [UK], 2012, p.19)

7.1   Individuals with high support needs often fail to receive the community support they need for good quality outcomes. However, they typically experience better outcomes in the community than in institutional settings where they are disproportionally represented (Kim et al., 2001; Mansell et al., 2010). Living in an 'ordinary environment' is necessary for good quality outcomes for people with high support needs, but it is not sufficient; activity, personnel and effective assistance are also needed (Felce, 1998 cited in Kozma et al., 2009). Research in relation to three groups of individuals with higher support needs is reported here: those with behaviours that challenge; persons with profound and/or multiple disabilities; and older persons with intellectual disabilities.

INDIVIDUALS WITH BEHAVIOURS THAT CHALLENGE

7.2   Behaviours that challenge, such as self-injury and various forms of aggression, may partially result from social and physical conditions, such as low staff numbers and experience, poor quality environments, and few available opportunities (Mansell, 2007). Such behaviours may also be seen more commonly in certain groups of individuals, e.g., those with intellectual disabilities who also have autism spectrum disorder (Felce, Perry, Lowe & Jones, 2011).

7.3   Behaviours that challenge are a primary reason for institutionalisation (Matson & Neal, 2009) and disproportionately more individuals who exhibit these behaviours are found in institutions. In the UK, for example, where deinstitutionalisation has progressed well by international standards, 7% of those in community services have behaviours that challenge, compared to 30% of those living in institutions (Hassiotis & Hall, 2004).

7.4   People with behaviours that challenge often experience diminished outcomes. They are more likely to live in larger, congregated settings; to experience poorer outcomes in community settings; to be excluded from community settings; to be re-institutionalised; to experience abuse; or to live 'out of area', isolated from family and other natural supports (Bigby, 2012; Hassiotis et al, 2008; Mansell et al., 2004).

7.5   These individuals are more likely to experience restrictive practices such as seclusion, physical restraint or mechanical restraint (Merineau-Cote & Morin, 2013), and to receive psychotropic medication for behaviour control. Prescription patterns remain unchanged following deinstitutionalisation (Matson & Neal, 2009). This practice is described as 'risky' and poorly evidenced (Matson & Neal, 2009, p.582).

7.6   Demonstration programmes show that individuals with behaviours that challenge can experience good quality of life in small, well-supported settings (Mansell, McGill, & Emerson, 2001). An extensive survey of 427 individuals in 146 community staffed houses in England

found that individuals with behaviours that challenge participated equally in social, community and household activities compared with others who did not (Felce et al., 2011). Despite evidence that equitable activity engagement can be achieved, the development of community-based services for this population is perceived by some to have failed (Jones, 2013). Negative social and professional attitudes are unchanged after moves from institutional to community services (Hubert & Hollins, 2010).

7.7   Moreover, placement breakdown in the community continues to be a widespread problem (Mansell, 2007). Difficulties are more likely to arise, with certain organisational features – for example, in settings where staff receive less training, supervision and external professional support (Broadhurst & Mansell, 2007). Staff attributions of the level of control an individual has over their behaviours have also been identified as a key predictor of placement breakdown (Phillips & Rose, 2010). These, and other issues, may contribute to the finding that, contrary to policies of good practice, community teams in the UK are often unable to support this population locally (Hassiotis et al., 2008).

7.8   Out of area placement, i.e., living outside one's geographical area of origin or funding base, may be presented as an option where appropriate local services cannot be sourced. These placements are more likely where people have significant behaviours that challenge; are younger; or have multiple health problems (including mental health) or autism spectrum disorders (Hassiotis et al., 2008).

7.9   Out of area placements are deemed a reactive response for those with higher support needs (Mansell, Beadle-Brown, Whelton, & Hutchinson, 2006) and have been criticised for echoing institutional provision (Perry et al., 2007). They are also considerably more expensive than local services, yet result in diminished outcomes for some who avail of this service. An evaluation of 54 organisations in the greater London area, for example, reported considerable quality variation among providers of out of area placements, with private providers most likely to under-perform (Andrea-Barron, Hassiotis & Paschos, 2011).

7.10   Service providers have been criticised for failing to consider returning individuals to their area of origin where behaviours have reduced (Hallam & Trieman, 2001). A reluctance to discharge may be due to lack of reviews, a lack of appropriate local accommodation, or negative perception by community teams of their ability to manage these individuals (Beadle-Brown, Mansell, Whelton, Hutchinson & Skidmore, 2005). Loss of family relationship may also result in difficulties with securing local services (Beadle-Brown, Mansell, Whelton, Hutchinson & Skidmore, 2006).

7.11   A 2007 audit in England of assessment and treatment units for individuals with behaviours that challenge identified 333 individuals, 75% of whom had a mild or moderate intellectual disability. A quarter had lived in the setting for over two years and fewer than half of them had a discharge plan. The researchers expressed concern about increasing, prolonged use of out of area assessment and treatment units (Mackenzie-Davies & Mansell, 2007).

7.12   A devastating example of inappropriate and unacceptable practices in an out of area placement was seen recently in the UK. Winterbourne View Hospital was originally designed to provide appropriate support for individuals with intellectual disability, many admitted under the Mental Health Act. When the scandal broke, half of those living in the hospital were out of area, some from over 100 miles away; many experienced long stays with little consideration of discharge (Department of Health [UK], 2012).

7.13   Staff at Winterbourne had systematically abused the individuals living there and 11 were convicted for "horrific and sustained abuse, ill-treatment and neglect" (Department of Health [UK], 2012, p. 16). Staff were poorly trained, with high rates of turnover and absences.

Clearly, the very high placement costs in this setting bore no relationship to the quality delivered.

7.14   The abuse of people living in Winterbourne went unnoticed by many agents including the police, the local Accident and Emergency Unit, and the safeguarding unit at the local council. The scandal revealed failures at multiple levels including the commissioning body, the Mental Health Act Commissioner and the Care and Quality Commission (CQC). Indeed, the CQC had inspected the hospital and reported it was functioning well (Department of Health [UK], 2012).

7.15   The Winterbourne scandal triggered a review across England of residential settings for people who engage in behaviours that challenge, which found "widespread poor quality of care, poor care planning, lack of meaningful activities to do in the day and too much reliance on restraining people" (Department of Health [UK], 2012, p.18).

7.16   The UK Department of Health Final Review concluded that "people with challenging behaviour benefit from personalised care, not large congregate settings" (Department of Health [UK], 2012, p.19), stating that it should be the norm to "live in their own homes with the support they need for independent living within a safe environment. Evidence shows that community-based housing enables greater independence, inclusion and choice, and that behaviours that challenge lessen with the right support" (Department of Health [UK], 2012, p.19). The Review further called for a "dramatic reduction in hospital placements […] stronger regulation and inspection, quality information and clearer accountability developing a supportive, open and positive culture in our care system" (p. 5).

7.17   Exemplary services for people with behaviours that challenge should be individualised effective, multi-disciplinary models of care, with good front-line management, co-ordination of multiple services, and investing in relationships between individuals, their families, staff and services (Mansell, 2007). Furthermore, environments should be supportive, with subtle and flexible application of a practice framework (Clement & Bigby, 2011).

7.18   Clearly, greater investment in local services would reduce reliance on out of area placements (Hassiotis et al., 2008). Local boroughs/authorities, voluntary and independent service providers should engage in creative collaboration, share information about providers delivering good quality care, and streamline the review process for these individuals. Making such changes is, however, "likely to be a challenge to entrenched ways of working" (Hassiotis et al., 2008, p. 444). Where local community services have been realised in parts of the UK and Australia, specialist community intellectual disability teams have achieved better outcomes and cost savings (Beadle Brown et al., 2005). Behaviour management strategies, debriefing opportunities, and staff training in providing supports under duress may all contribute to quality services for this population (Ravoux, Baker & Brown, 2012).

7.19   In conclusion, researchers and policy makers often consider it a 'fait accompli' that individuals who exhibit behaviours that challenge will have limited access to their local communities (Bigby, 2012). Out of area placements have failed to deliver on acceptable outcomes for this group. New options respecting their dignity and needs are required. For Professor Jim Mansell, the inclusion of people who engage in behaviours that challenge is in fact 'the acid test of the policy of community care" (Mansell, 2007; p.28).

7.20   Adults with profound intellectual and multiple disabilities are a relatively small group with high support needs who often do not receive adequate services (Mansell, 2010). In poorly staffed institutional settings, they are often physically and socially neglected. Even with more staffing, co-ordination to achieve quality individualised care is challenging (Mansell, 2010).

7.21   Research has explored whether it is beneficial to group people with similar diagnoses or support needs, a practice that may reflect efforts to provide more personalised, tailored support (Mansell et al., 2003). However, evidence suggests that no quality of care or lifestyle outcomes are associated with grouping people with similarly complex support needs (Felce & Perry, 2012; Mansell et al., 2003; Robertson et al., 2004).

7.22   In the UK, Professor Jim Mansell conducted an extensive review of services for those with high support needs, *Raising Our Sights* (Mansell, 2010); its findings are briefly presented here. The review noted that good services should be individualised and person centred; service providers should treat family as experts in supporting their family member; the quality of the relationship between staff members and the supported person should be prioritised; services should offer continuity of support; and good supports should be cost effective.

7.23   In countries where deinstitutionalisation is more advanced, such services are more plentiful (Kozma et al., 2009). Where good support is available, e.g., in Sweden, individuals with more severe disabilities who move to the community are more satisfied than they were with former congregated settings (Ericsson, 2000).

7.24   However, individualised, flexible community care that optimises choice for these individuals can be hampered by funding pressures and a culture of control (Mansell & Beadle-Brown, 2004). Service providers may focus on cost savings, failing to recognise the cost-effectiveness of higher quality services. Community-based services will be lower cost because supported people will avail of local health services (Mansell, 2010). In particular, *Raising Our Sights* was critical that there were few opportunities for family members to engage in more self-directed services, where they are facilitated to purchase and manage supports. Mansell argues that such personalised supports are particularly suitable for those with significant support needs.

7.25   Good support can also be hampered by staff attitudes towards those with higher support needs. An innovative and informative ethnographic study explored staff attitudes to people with more severe levels of intellectual disability as they moved from institutional to community living (Bigby, Clement, Mansell & Beadle-Brown, 2009). Despite having long-standing exposure, staff were found not to extend their deeply-held beliefs in full inclusion of all persons with disabilities to those with high support needs. An attitude prevailed of 'let's be realistic, it's not feasible with this group'. The authors questioned whether people with high support needs are inadvertently excluded by the de-differentiated approach of many disability policies. To address this, they call for more explicit guidelines on how policies should be interpreted for those with complex needs.

7.26   *Raising Our Sights* calls for government policy and resources to be made available to ensure that appropriate services are developed for this group of individuals. These resources include supports for families, access to advocacy and the use of assistive technology. Of particular importance is the call for induction, in-service training, and new qualifications for those charged with the very skilled task of supporting a person with profound and multiple disabilities (Mansell, 2010).

7.27   The life expectancy of people with intellectual disabilities has increased 'more dramatically' in recent decades than that of the general population (Bigby, 2010). Combined with this, however, is an increase in illness. Trends among the health status of older people with intellectual disabilities are currently monitored in an extensive Irish study allied to the Irish Longitudinal Study on Aging (TILDA). IDS-TILDA, the intellectual disability strand of TILDA, explored the prevalence of 12 chronic conditions in 753 persons aged 40 years and over with an intellectual disability. Most (71%) reported multiple health conditions. Even among the youngest age group, 40-49 years, 63% had multiple co-morbidities (McCarron, Swinbourne, Burke, McGlinchey, Carroll, & McCallion 2013). The most prevalent was a combination of neurological and mental health diagnoses. In these circumstances, suitable living options are a pressing need (Weber & Wolfmayr, 2006).

7.28   Many older persons with intellectual disabilities currently live at home with ageing carers and are likely to require transition to alternative housing and support services (O'Rourke et al., 2004; Shaw, Cartwright & Craig, 2011). Their caregivers can be fearful of considering future changes (Innes et al., 2012). Some who moved older family members with intellectual disability into specialist aged-care residential facilities reported having made this decision in haste, seeing aged care as a 'fait accompli' and not having considered ageing in place (Bigby, Bowers & Webber; 2010; Bigby et al., 2008; Heller et al., 2008).

7.29   The Graz Declaration on Disability and Aging supports home care and independent living options, while acknowledging that a disproportionate number of older people with intellectual disabilities live in residential aged care (Weber & Wolfmayr, 2006). There is, however, a lack of alternatives in some countries. In Australia and the UK, for example, many people with intellectual disabilities moved to aged care facilities from the family home not because their needs changed, but because of organisational change or the ageing or death of a family carer (Bigby, Webber, Bowers & McKenzie-Green, 2008; Thompson, Ryrie & Wright, 2004). Such admissions may also reflect inappropriate referrals from inexperienced staff in generic memory clinics, unfamiliar with the needs of people who have intellectual disabilities (McCarron & Lawlor, 2003).

7.30   People with intellectual disabilities living in aged care facilities for the general population tend to be younger and are less likely to have dementia than others in these settings, and are thus poorly matched (Putnam, 2004). In these facilities, they have limited opportunities for social inclusion, day services, family relationships, and support from outside professionals (Thompson et al., 2004).

7.31   People with intellectual disabilities and their caregivers have been reported to prefer housing and supports that enable them to maintain or enhance social networks as they grow older (Shaw et al., 2011). Older persons with intellectual disabilities typically, however, report shrinking social networks, with many reporting that they are 'known well by no-one' (Bigby, 2008).

7.32   Individuals with intellectual disabilities themselves have expressed concern about their future accommodation, and about a lack of choice and information about their own future. These findings indicate that they require greater consultation regarding their future living arrangements (Innes et al., 2012).

7.33   Bigby (2010) conducted an extensive review of accommodation support policies for older people with intellectual disabilities across five countries: Australia, Canada, Ireland, the UK and the US. In these countries, ageing policies for people without a disability prioritise

remaining at home even when needs increase. Bigby argued that people with intellectual disabilities should equally be supported to exercise their right to 'age in place', noting that despite over 15 years of pilot projects services have not translated into policy. Joint working between aged care and disability systems, though essential, was rare. Moreover, where specific procedures supported ageing in place, this was typically coordinated at local rather than at national level (Putnam, 2004).

7.34   The need to address ageing among people with intellectual disabilities was cited in national policies of four of the five countries (except Canada). These references were, however, according to Bigby somewhat vague. Ireland was identified as the only country backing specific supports for those with intellectual disability who are ageing. The source is a 1998 Eastern Health Board Action Plan for Services for Older Persons advocating that "in order to ensure that older people with a mental handicap receive specialist services appropriate to their needs it will be necessary for the mental handicap agencies to develop appropriate services". Current data for Ireland however reveals that people with intellectual disabilities aged over 40 are more likely to be supported in congregated rather than community-based settings (McConkey, Kelly, Craig, Mannan, 2013).

7.35   The residential needs of older individuals with intellectual disability with dementia have also received attention. In a survey of the needs of 35 individuals with Down's Syndrome diagnosed with dementia, fewer than expected had changed their residential circumstances and most caregivers were unclear about future accommodation (Watchman, 2008). This suggests that although moves are not common during the early stages of dementia, it is a time when people themselves could contribute their views, yet planning was often left to family when the dementia had progressed to a later stage (Watchman, 2008).

7.36   Recent guidelines have been developed as part of the US National Strategy addressing Alzheimer's Disease, establishing a National Task Group on Intellectual Disabilities and Dementia Practices. This group was charged with formulating practice guidelines for health and social care supports, and recommending models of community-based support for individuals with intellectual disabilities who had dementia (National Task Group on Intellectual Disabilities and Dementia Practices, 2012). Guidelines are provided across residential options including the family home, own home, group home or apartment living, or 'specialist' homes defined as community dwellings supporting 'clusters of people with dementia'. All options seek to maintain individuals in the community despite their deteriorating abilities (Jokinen et al., 2013).

SUMMARY: THOSE WITH HIGHER SUPPORT NEEDS

7.37   People with intellectual disability with higher support needs are represented here by three groups: those with behaviours that challenge, those with profound and multiple disabilities, and those who are ageing. Services struggle to provide good quality outcomes for all groups. People with behaviours that challenge are over-represented in institutional or out-of-area placements. The Winterbourne scandal is a stark reminder of the need for constant vigilance for this vulnerable group. Those who have profound and multiple disabilities may also experience diminished outcomes including physical and social isolation. *Raising Our Sights* provides a welcome reflection on how good services can and should be provided. Finally, for individuals with intellectual disability who are ageing, services struggle to provide the optimal support of ageing in place. Good practices and guidance are available for service development for those with higher support needs; indeed, as Prof Jim Mansell has noted, these services provide an 'acid test' of policies advocating community living.

8. Supporting Life in the Community (II): Social Inclusion

*The success or failure of deinstitutionalisation will rest with our ability,
collectively, to prepare our communities to accept persons with (intellectual)
disabilities as valued and contributing members of our society.*

(Gallant, 1994, cited in Bigby & Fyffe, 2006, p.569)

8.1 Social inclusion and community participation lie at the heart of normalisation and social role valorisation. They are also rights under the United Nation's Convention on the Rights of Persons with Disabilities (United Nations, 2006), which requires States to take effective and appropriate measures to facilitate the full inclusion and participation of people with disabilities.

8.2 Informal social relationships are particularly important for quality of life, and community living should facilitate social inclusion, promoting relationships among people with disabilities, their friends, neighbours, colleagues, local shopkeepers and other community members (Bigby, 2008). Disability specific services should aim to enhance, not replace these important relationships (Mansell et al., 2010). There is evidence, however, that people with disabilities are twice as likely to experience social isolation from family and friends compared with the general population (National Disability Authority, 2011b).

8.3 Recent Irish policy reports have highlighted the importance of 'natural supports' for individuals with intellectual disabilities (Duggan, 2011; Duggan & Linehan, 2013). The Expert Reference Group of the Value for Money and Policy Review of Disability Services (Department of Health, 2011) defined natural supports as "extended family, friends, neighbours" who should - with family members - be the "first line of supports, followed by informal and community supports, to formalised individual supports" (p. 15). Moreover, the Review proposed that enhanced family and community supports would achieve greater cost-effectiveness. The evidence base for natural supports is, however, extremely limited (Duggan & Linehan, 2013).

8.4 As noted in section 3.10 above, there is considerable evidence that people with intellectual disabilities experience substantially improved social inclusion when living in community settings compared to institutions. However, despite being physically included in the community, many individuals had "little sense of belonging and membership, and few meaningful relationships with non-disabled community members" (Amado, Stancliffe, McCarron & McCallion, 2013, p.360). McConkey, Abbott, Walsh, Linehan and Emerson (2007) also noted that people with intellectual disabilities have little access to community amenities and are often socially isolated with consequent effects on health and well-being.

8.5 Most communities have a record of discrimination and exclusion (Mansell et al., 2010). In the Netherlands, research indicated that communities and neighbourhoods consider the inclusion of people with intellectual disabilities not to be their responsibility, but rather to be a matter for people with disabilities themselves, their families, and government (Nieboer et al., 2011).

8.6 In Ireland, families of people with intellectual disabilities noted that society's attitudes towards disability were improving over time, and that stigma was reducing, although members of the public continued to be awkward, embarrassed or fearful when interacting with their family member. Families also reported instances where relatives with intellectual disabilities were avoided, excluded, made fun of or bullied (Chadwick et al., 2013).

8.7   An insight into the general population's attitudes toward disability in Ireland can be gleaned from a nationally representative survey of over 1000 adults (National Disability Authority, 2011b). The survey was a follow up to baseline surveys conducted in 2001 and 2006. Respondents were asked how 'comfortable' they would be if people with different types of disabilities moved into their neighbourhood. Interestingly, the level of comfort expressed with people with disabilities moving into the neighbourhood was higher than for other marginalised groups such as members of the travelling community, ethnic minorities and people from other cultures, and lesbian, gay, bisexual or transsexual people. However, follow up data revealed a 'hardening' of attitudes towards people with disabilities, particularly mental health and intellectual disability/autism spectrum disorder, which were less favourably endorsed than physical disability. The main concern was the possibility of people with disabilities engaging in disruptive or dangerous behaviours.

8.8   Poor social inclusion and community participation of people with intellectual disability should be seen as a major concern (Ericsson, 2000), particularly when evidence suggests that community links for people with intellectual disabilities do not mature over time, but remain low (Hall & Hewson, 2006). In the sections below, we outline how social inclusion is conceptualised, and identify factors affecting inclusion of people with intellectual disabilities in their local communities.

WHAT IS SOCIAL INCLUSION AND WHAT HAVE STUDIES MEASURED?

8.9   Although social inclusion is central to disability policy, there is little clarity about its meaning. O'Brien (1987) pioneered the distinction between 'community presence' – the sharing of ordinary places – and 'community participation' – the experience of being part of a social network of people, other than those comprising people with intellectual disabilities, immediate family and staff. However, many terms are used interchangeably and it is unclear whether different terms reflect different concepts, though some researchers have attempted to distinguish between integration, inclusion, participation and belonging (Amado et al., 2013; Bigby, 2012; Cobigo & Stuart, 2010; Martin & Cobigo, 2011).

8.10   'Social inclusion' may therefore assess factors such as living situation, acquaintances, friendships, social interaction, employment (paid or voluntary), use of community and commercial facilities, meaningful community activities, or even simple frequency assessments of how often individuals use community facilities or see their friends (Bigby, 2012).

8.11   Frequency assessments are the most common method used to research social inclusion. Others include 'choice' assessments and 'intensity' assessments. Choice assessments aim to measure self-determination in social and community activities; intensity assessments, the most challenging, attempt to factor in personal preferences (Amado et al., 2013).

8.12   Frequency assessments have been critiqued for being superficial (Bigby, 2012), but they can provide valuable information. The Irish longitudinal study of older people with intellectual disability (McCarron et al., 2011), for example, found that of 753 people with intellectual disabilities in Ireland aged 40 and over, a quarter met family once a year or less; over three-quarters never used any mode of communication to contact family or friends; half sometimes felt lonely; and fewer than one in five received help from neighbours. Three-quarters named a keyworker as their major confidant. These simple frequency counts provide insight into the widespread lack of social inclusion.

8.13   Studies have also examined the breadth of social networks of people with intellectual disabilities, consistently showing that social networks rarely include people other than staff or

other people with intellectual disability (Amado et al., 2013). Reported medians of social networks are 2-12 persons, in stark contrast to the median of 125 persons cited in the social networks of people without disabilities (Amado et al., 2013). Recently, research has begun to focus on loneliness, and has found it is more widespread among persons with intellectual disabilities compared with the general community, with up to half reporting that they felt lonely. This loneliness often reflects the absence of an intimate partner (Amado et al., 2013).

8.14 While undoubtedly informative, research on social inclusion has been criticised for focusing almost exclusively on the individual with intellectual disability. There is, according to Bigby (2012) a 'complete absence' of research focusing on the perspective of the receiving community, that is, the inclusive nature of locally based clubs and organisations.

FACTORS INFLUENCING SOCIAL INCLUSION

8.15 Despite decades of deinstitutionalisation, with a fundamental expectation of community inclusion, the social networks of people with intellectual disabilities remain restricted (Bigby 2008; Forrester et al., 2006; Milner & Kelly 2009).

8.16 Several factors have been linked to social inclusion. Perhaps unsurprisingly, an individual's level of social competence is a significant predictor (McConkey et al., 2007). The following environmental factors were also found to affect community participation, in a review of 11 studies: autonomy/choice opportunities; smaller settings; variety and stimulation in the environment; vocational services; and access to transport (Verdonschot, de Witte, Reichraft, Buntix & Curfs, 2009). Amado et al. (2013) note that "regular contact in integrated environments, with opportunities for meaningful inclusion" is critical (p. 363).

8.17 These findings echo views of people with intellectual disabilities about barriers to their social inclusion, who identified four key barriers: personal abilities and skills, insufficient or unsupportive staff, poor attitudes and accessibility within the community, and most notably, significant challenges with transport (Abbott & McConkey, 2006).

8.18 Facilitators of social networks of people with intellectual disability have been proposed in the literature, although there is little research to draw on. Duggan and Linehan (2013) summarised four strategies. *Circles of support* engage family and friends in a formalised structure to support a person with intellectual disability to achieve personal goals. In *peer-based approaches*, people with disabilities support one another, sharing experiences through peer counselling; they are typically facilitated in 'drop in' centre environments. *Training programmes* assist development of social skills to enhance social inclusion opportunities. Finally, with *befriending strategies*, volunteer 'community connectors' or 'community inclusion officers' in disability organisations form friendships with persons with disabilities. These initiatives are widely enjoyed by people with disabilities, but few are formally evaluated; more rigorous research on their effectiveness is required.

The impact of residential setting on social inclusion

8.19 Overall, living in smaller settings is associated with more community participation (Verdonschot et al., 2009). Supported living options, whether dispersed or clustered, have been reported to promote higher levels of social inclusion (in terms of social contacts and use of community amenities) when compared with other living arrangements such as fully staffed community group homes, residential homes or campus-based options. However, it is important to note that an individual's level of social competence is also a key predictor of community involvement (McConkey et al., 2007).

The impact of staff attitudes and practices on social inclusion

8.20   Staff attitudes and practices may affect social inclusion even more than living arrangements (McConkey & Collins, 2010a). More individualised management practices, for example, are associated with greater community presence (Emerson & McVilly, 2004; Felce & Emerson, 2001). Person-centred approaches can increase contact with friends and family and increase community participation (Robertson et al., 2006), so individual support is central to support people to achieve personal goals (McConkey & Collins, 2010b).

8.21   Staff attitudes may also differ by living arrangement. Staff in supported living schemes give higher priority to social inclusion tasks than staff in shared residential homes, group homes and day centres (McConkey & Collins, 2010a). In all settings, however, staff prioritising of social inclusion tasks varies widely and is often low (Clement & Bigby, 2007; Felce, Mansell & Kushlick, 1980; Hewitt et al., 2004; McConkey & Collins, 2010a). Even when staff job descriptions specifiy goals of maintaining informal relationships and building new ones, these goals may not be present in individuals' plans, or may not be implemented (Bigby, 2008). This may be particularly the case for individuals with more severe intellectual disabilities, where staff simply do not consider such principles valuable or feasible to apply (Bigby et al., 2009).

8.22   Staff attitudes to inclusion may also vary with demographics (Jones, Ouellete-Kuntz, Vilela, & Brown, 2008). Jones et al. found in a study of 241 staff in intellectual disability services in Canada that male staff were less positive to inclusion than female staff; that staff with higher education were more likely to think of supported people as similar to themselves; and that older staff were more inclined to believe supported people needed protecting from harm. The authors note that many staff hold views that are not compatible with philosophies of inclusion and that targeting particular staff groups in inclusion education may ensure greater success.

8.23   People with intellectual disabilities call for greater support in creating and maintaining community relationships (Duggan & Linehan, 2013). Services therefore need to "develop active strategies to nurture and build informal social networks" (Bigby, 2008, p. 155). One solution may be to develop dedicated 'link' workers whose primary task is to develop social connections (Halliday & Asthana 2004; Stalker, Mallock, Barry & Watson, 2007) through mapping family connections, supporting ongoing family engagement, and developing creative strategies to foster friendships or advocacy relationships (Bigby, 2008). Few such schemes, however, have been formally evaluated (Duggan & Linehan, 2013).

8.24   People with intellectual disabilities stress that staff need to move from a caring to a supporting role, and to assist them in acquiring skills for using money, travelling independently, and navigating the local area (Abbott & McConkey, 2006). To do this, staff need to develop 'active support' skills and re-evaluate perceptions of risk that may, inadvertently limit social inclusion. More information on active support is reviewed in Section 9.

Neighbours and communities

8.25   In the 1970s in the US, there was sometimes 'virulent' and 'intense' hostility, even dangerous attacks on homes, when people with intellectual disabilities first moved to the community (Parish, 2005). More recent research reports more positive community attitudes. Neighbours' contact with people with intellectual disabilities was associated with more positive attitudes to community living (Robertson et al., 2004). Families in Ireland interviewed recently reported lower levels of stigma in the community (Chadwick et al., 2013).

8.26   Other studies, however, reflect less positive situations. People with intellectual disability living independently have reported victimisation by people without disabilities (Emerson & Hatton, 1996). Neighbours saw people with intellectual disabilities as a separate community, different

from others in the locality, particularly where they lived in cluster developments. They perceived group homes as a business, with features that impeded neighbour relationships, such as high turnover of residents, staff on site, and group activities (Van Alphen, Dijker, Borne, & Curfs, 2009). Neighbours express concerns about a lack of reciprocity, accountability and appropriate social distance from neighbours with intellectual disabilities (Van Alphen, Dijker, Borne, & Curfs, 2010).

8.27   People with intellectual disabilities often have limited interaction with neighbours, and are dependent on staff or the service organisation to function as mediators (Abbott & McConkey, 2006; Cummins & Lau, 2003; Overkamp, 2002; Todd, 2000; Van Alphen et al., 2009). In a UK study of both congregate and community settings, two-thirds of neighbours did not know any service users by name and one-third had no active contact with them (Robertson et al., 2004). In their views, community attitudes need to change to counter bullying and to create a positive welcome for their participation in the community (Abbott & McConkey, 2006).

8.28   Community characteristics that lead to greater integration are not known (Amado et al., 2013; Felce & Emerson, 2001). Parlalis (2009) concluded that communities need to be educated about the nature and purpose of deinstitutionalisation.; as noted above, communities in the Netherlands consider it others' responsibility to facilitate inclusion (Nieboer et al., 2011). Amado et al. (2013) argue that social inclusion research should include views and experiences from the community rather than focusing solely on experiences of people with intellectual disabilities. They also call for community projects to increase social connectedness.

SUMMARY: SOCIAL INCLUSION

8.29   Social inclusion and community participation are a right for people with disabilities. After many decades of deinstitutionalisation, however, full inclusion remains elusive. Natural supports are seen as an untapped resource to enhance inclusion. In addition, smaller settings, transport, opportunities for community participation, and social competence may contribute to greater inclusion. Moreover, resources are particularly required to address attitudes of staff who prioritise care tasks over social inclusion. Finally, the views and inclusive behaviours from neighbours and community members should also be addressed.

9. Supporting Life in the Community (III): Advocacy and Active Support.

9.1   At a time of significant change in disability support services, many practices and structures need to be addressed to enhance the delivery of more personalised and individualised supports. In this section, two areas are explored, active support and advocacy, as exemplars of methods aiming to optimise quality outcomes for individuals, and ensure that their voice is kept central to any proposed changes in their support services.

I'd say it's about […] helping each other and sticking up for each other

(Beart, Hardy & Buchan, 2004, p.95)

9.2   Although advocacy as a movement for people with intellectual disabilities has existed for almost three decades, it is still considered relatively under-developed (Goodley, 2000). The move towards greater inclusion and participation in community life will require people with intellectual disabilities to be more actively involved than past generations. With this expectation of greater choice and control comes an expectation that they will be decision makers in their own right (Department of Health, 2011).

9.3   Different forms of advocacy exist, including self-advocacy (empowering people to speak for themselves); peer advocacy (supporting others to do so); group advocacy (self-advocacy in a group format); citizen advocacy (using unpaid volunteers); and professional representative advocacy (paid advocates, typically in complex situations) (Citizens Information Board, 2010). However, they may operate on a continuum so distinctions between them may be artificial.

9.4   People with intellectual disability in Ireland have called for advocacy for privacy and accommodation. They have also called for more accessible information on social welfare entitlements, and on the implications of reductions in services. A particularly important call was for advocacy services to be provided independently of organisations that individuals were already receiving services from (McCann, 2009).

9.5   Cambridge and Ernst (2006) explored formal advocacy services across Europe to identify approaches to user representation, complaints procedures and advocacy. Cultural influences and rights traditions were reflected in local variations in user, carer and parental involvement; for example, parent advocacy is strong in Germany, self-advocacy in England and citizen advocacy in Sweden. There were complaints procedures in most countries although these may lack objectivity, as most are located within services. Legal challenges are also possible with variations of the Ombudsman model in many countries.

9.6   However, Cambridge and Ernst (2006) argue that "there remains considerable scope for developing stakeholder models of representation in services and for the further promotion of self-advocacy and investment in models of professional advocacy through social work" (p. 300); and that, crucially, managers and practitioners need to respect differences and work in "valued ways" with people in intellectual difficulties. To do so, managers need to "hand over more power" to service users, self-advocacy groups and professional advocates such as social workers.

9.7   Chadwick et al., (2013), in an extensive participatory consultation across Ireland, noted that family members rarely mentioned advocacy directly, yet much of what they spoke about across the lifespan of experiences with family members with intellectual disabilities reflected advocacy roles. They discussed (i) raising awareness and attitudes in the community, with services and the government; (ii) checking that services supported their family members well and, most often, (iii) fighting for services. Their stories described tenacity over decades of fighting as well as the strain of simultaneously advocating and caring. They also described "frustration, anger, resignation, exhaustion and household stress" (p. 126) in the process.

9.8   The need to raise awareness about advocacy among those supporting people with intellectual disabilities is underlined by recent UK findings from Da Silva Martins, Willner, Brown and

Jenkins (2011), who explored awareness of the Independent Mental Capacity Advocate (IMCA) service among community intellectual disability teams. Only half correctly identified the purpose of advocacy as representing clients' views, and there was negligible understanding of situations that should trigger IMCA service referral: only 1 of 22 staff identified the statutory requirement to involve an IMCA for a change of long-term accommodation where the person lacks capacity and has no other non-professional support, and none identified this statutory requirement in relation to serious medical treatment. Da Silva Martins et al. (2011) concluded that training needs to address these deficits.

9.9   Overall, therefore, despite offering benefits, advocacy services remain under-developed. Staff have been found to be unfamiliar with formal advocacy processes, family members engage in advocacy yet do not recognise their efforts as such, and people with intellectual disabilities call for independent advocacy supports across a range of life domains. As models of personalised, individualised supports are developed it is important that necessary advocacy structures are simultaneously developed, to ensure that the voice of people with intellectual disabilities and their family members are appropriately represented.

ACTIVE SUPPORT

In many community services, as in institutions, people with intellectual disabilities spend large amounts of time literally doing nothing.

(Mansell, Elliott, Beadle-Brown, Ashman & Macdonald, 2002; p.343)

9.10   Active support is a key component in the ongoing post-closure deinstitutionalisation process. It is a "powerful technique" for improving the lives of all people with intellectual disabilities (Mansell et al., 2002), and counteracts the inactivity, passivity, boredom and isolation experienced by many even after moving to the community.

9.11   In community settings, engagement in activities is particularly important as it is "the vehicle by which many aspects of quality of life are realised" (Mansell, Beadle-Brown, Whelton, Beckett & Hutchinson, 2008, p.398). Active support requires staff to shift from traditional caretaking approaches to a focus on supporting and reinforcing individuals' engagement in meaningful activities in which the individual has an interest (Mansell et al., 2002). It can only be achieved in a person-centred environment, and therefore cannot be successfully implemented in hospitals, villages, or cluster housing schemes (Mansell & Beadle-Brown, 2010).

9.12   Active support has four components: (i) individuals are offered opportunities to take part in everyday activities at home and in the community, taking account of their preferences; (ii) staff co-ordinate routines, choices and opportunities; (iii) staff provide support for minute-by-minute participation with graded levels of assistance; and (iv) staff monitor and keep records of the level of participation (Mansell et al., 2002).

9.13   Staff activity and support are the most important factors determining levels of meaningful activity for people with intellectual disabilities (Mansell et al., 2008). However, many people living in staffed housing receive little facilitative assistance, typically less than 10 minutes per hour (Felce, Lowe & Jones, 2002), sometimes substantially less (McConkey, 2000). They may be waiting for long periods for staff to complete various tasks. Instead, they could be engaged in the very tasks – usually domestic tasks – that staff are carrying out (Mansell,

Felce, de Kock & Jenkins, 1982), which would promote gains in quality of life (Felce & Toogood, 1988).

9.14   The role of organisations in the degree to which active support is implemented is not clearly understood, but there are indications of factors involved (Fyffe, McCubbery, & Reid, 2008; Mansell & Beadle-Brown, 2012). These include characteristics of the setting (type and size of service); good and practical leadership, including line management; management (autonomy and systems for organising care); staffing (ratio; qualifications and experience; training; turnover; and attitudes); as well as job satisfaction, stress, role clarity and conflict.

9.15   The wider organisational context is also important (Mansell & Beadle-Brown, 2012). Mansell et al., (2008), for example, found that staff factors associated with successful active support were clear management guidance; frequent supervision and team meetings; and training and staff support. None of these, however, consistently predicts good care practices, and different factors may be specific to particular service models (Mansell & Beadle-Brown, 2012).

9.16   To support development of active support and new staff care practices, models of good practice should be promoted (Mansell, Beadle Brown & Clegg, 2004). To implement good quality community supports, staff need to observe its benefits, and they need opportunities to shadow more experienced colleagues (Cambridge & Ernst, 2006, Nieboer et al., 2011).

9.17   There is substantial evidence that community-based services lack training for direct care staff, yet this is key to implementing active support (Parsons, Reid & Green,1993; Parsons & Reid, 1995). Underperformance of community settings can be addressed with staff training (Fujiura, 2006); indeed, Jones et al. (2001) found that staff performance did not change, and engagement did not improve, if service managers had not included hands-on staff training.

9.18   To implement active support for people with intellectual disabilities, Mansell and Beadle-Brown (2012) summarised four stages of change an organisation needs to carry out:

(1)   *Creating enthusiasm*: A clear message is needed to harness motivation in staff, people with intellectual disability and their families. Management need to raise awareness about how quality of life can be improved; early champions should be sought out. A powerful communication tool is hearing about or seeing good practice.

(2)   *Commitment to innovation*: After creating motivation for change, a space must be created for change to take place. Senior managers need to provide demonstrations; give assistance to early adopters; and release staff from previous practices.

(3)   *Full implementation*: Early learning from the innovation is used to implement the new practices and reshape the working of the rest of the organisation.

(4)   *Moving to excellence*: In the later stages of implementation, management should focus on those who fail to comply, providing assistance or dismissing them, as they will not only provide lower quality services, but may also undermine change.

9.19   Active support is an evidence-based model of support that aims to empower and enable people with intellectual disabilities to participate fully in all aspects of their lives. Although many individuals with disabilities living in the community enjoy stimulating and varied lives, others, particularly those with more complex needs, spend much of their time 'waiting'. Given the limited scope to improve aspects of adaptive behaviour, active support provides staff with the necessary skillset to promote greater engagement in meaningful activity by people with intellectual disability.

9.20   Advocacy and active support have been outlined briefly in this section to illustrate ways in which the process of deinstitutionalisation needs to continue after institutional closure. Moving towards more individualised models of support will require developing particular services to facilitate individuals to increase their opportunities in the community. In the absence of targeted practices that aim to facilitate individuals engage in meaningful activities and advocacy, it is likely that institutionalised and congregated practices may remain.

10. Supporting Life in the Community (IV): The Role of Organisational Factors

> *Organisation change efforts frequently fail because, regardless of the interventions(s) tried, leaders and managers have failed to change the deeply ingrained assumptions, generalisations and images that help organisation personnel understand the world and experience (or visualise) the future.*
>
> (Schalock & Verdugo, 2012, p.6)

10.1   As has been reiterated in preceding sections of this report, the goals of deinstitutionalisation are not achieved by simply physically relocating people with intellectual disabilities from institutions to community living. Unfortunately, it is the case that the facilities, structures and practices in some community settings echo institutional life; social inclusion in communities is still inadequate; and crucial supports such as advocacy and active support are often absent, with staff unaware of these practices, untrained in them, or rejecting principles of inclusion. Many further changes are required to achieve meaningful deinstitutionalisation, or inclusive, actively supported community living for people with intellectual disabilities.

10.2   Achieving change on this scale is no small task. It requires making changes to every level and facet of an organisation: to its aims, to attitudes of managers and staff, and to daily, on-the-ground support practices. It also entails undergoing a fundamental shift from a philosophy of 'care' to one of 'support' (Schalock & Verdugo, 2012). Organisations differ substantially in how successfully they have achieved this.

10.3   Achieving change from facility-based disability services to more individualised supports is an ongoing process that requires perseverance and commitment (Walker, 2012). A policy "push" for change, as currently exists in Ireland (Linehan et al., 2014a), can increase the chances of successful change, particularly if funding is provided. However, some organisations may not be motivated to change; if strongly identified with former values, or unable to detach from former structures or ways of working, they may not be able to achieve this, and will ultimately close (Moxley & Manela, 2000). Furthermore, even where policy increases organisations' *motivation* it does not necessarily increase their *capacity* to adopt novel ways of working (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004).

10.4   In Ireland, such change will mean developing new values ways of working in both HSE-run services, and in the non-governmental sector which dominates service provision for people with intellectual disabilities (Linehan et al., 2014a). However, successive service reviews and evaluations of disability services in Ireland indicate that this is likely to present a substantial challenge. These have consistently poor or non-existent implementation of change by both voluntary and statutory bodies over many decades (Linehan et al., 2014a).

10.5   Surprisingly, despite the scale of the task, and despite the great body of international research examining deinstitutionalisation, organisational factors are rarely researched (Nieboer et al., 2011; Walker, 2012). To understand how radical change in intellectual disability services may best be implemented, organisational structures and functions need to be considered, including factors that may support or impede change.

10.6   There is a large body of existing organisational change research, but this is generally business-oriented and frequently relies on anecdote rather than analysis (Hughes & Wearing, 2013; Oxman et al., 2005). In this section we have instead, wherever possible, drawn on empirical studies and systematic reviews of change conducted in human service organisations: those providing supports to individuals and families e.g. in social work, social care, community services, mental health and education as well as disability.

ACHIEVING CHANGE IN LARGE-SCALE HUMAN SERVICE ORGANISATIONS

10.7   Moxley and Manela (2000) argue that change processes in large-scale, complex human service organisations, such as disability providers, vary depending on the kind of change required. For changes to existing services, whether smaller-scale performance improvement, or more extensive systems change, they outline processes of *revitalisation* and *renaissance*. The most radical type of change, however, which Moxley and Manela term *recovery*, is the most relevant to deinstitutionalisation. Recovery is needed when a dramatic shift in social values leads to major policy change, requiring new organisational structures and practices. An exemplar of such a shift in social values was the application of normalisation to the lives of people with intellectual disabilities, as outlined in Section 2. Deinstitutionalisation then became necessary, which in turn required organisations to develop a new vision and radically new ways of working.

10.8   To achieve radical new ways of working, organisations need to reframe their internal culture, operations, and practices (Moxley & Manela, 2000). Therefore, deinstitutionalisation involves going beyond bricks and mortar and tackling organisations' values and culture. In their seminal systematic review of change in complex health service systems, cited in over 2000 academic publications, Greenhalgh et al. (2004) conclude that the success of such change is affected by both practical factors (such as cost, codification of knowledge, and training), as well as the interpretations and perceptions of those implementing the change.

10.9   Change, Greenhalgh et al. (2004) conclude, is more likely to succeed if it is introduced incrementally; if modified to suit the needs of those adopting it; if training and supports are provided; and if it has well-codified, transferable knowledge that can be customised to the context. Furthermore, change is also more successful if staff perceive that the current way of working is unsustainable; if the new way of working has visible benefits; if adopters perceive it as simple to use, or if practical demonstrations can reduce perceptions of complexity; and if it is compatible with organisational and professional values, norms, perceived needs and ways of working; and if it is considered more effective or cost-effective.

10.10 Greenhalgh et al. (2004) summarise six factors that influence readiness for change. In addition to addressing the factors above, organisations need to assess implications of the change; dedicate time and resources to it; and be prepared to evaluate its outcomes and make adjustments accordingly (Table 3).

Table 3: Factors influencing organisational readiness for change (Greenhalgh et al., 2004)

Tension for Change	Staff perception that the current situation is intolerable
Supporters for Change	Supporters should outnumber opponents, and be more strategically placed
Innovation-Organisation Fit	Innovation fits with the organisation's existing values, norms, strategies, goals, skill mix, technologies, and ways of working
Assessing Implications	Full assessment and anticipation of implications of the innovation has been carried out
Dedicated Time and Resources	Adequate and continuing allocation of resources
Capacity to Evaluate	Tight monitoring and evaluation systems and skills

10.11 An overall implementation and management plan is needed to achieve deinstitutionalisation, as implementation frameworks influence outcomes (Mansell et al., 2004; Meyers, Durlak & Wandersman, 2012). To develop a framework for achieving desired outcomes and meeting quality standards, Meyers et al. (2012) synthesised features of 25 successful implementation frameworks in complex human service systems. Reflecting the inherent challenge of change in human services, Meyers et al.'s framework involves 4 phases, 14 steps and 37 questions for organisations to address. The critical features of the framework are assessment, collaboration, negotiation, monitoring and self-reflection.

10.12 Finally, it should be noted that even if all the above features are in place, successful adoption of change cannot be guaranteed. Context plays a major role (Kitson, 2009; Walker, 2012). This includes the social and policy context, as well as features of the organisation, such as the flexibility of its structures and systems, and the characteristics and responses of individuals who will be implementing the change. Empirical studies therefore indicate that change in complex human services is often "organic and often rather messy … the organisation moves back and forth between initiation, development, and implementation, variously punctuated by shocks, setbacks, and surprises" (Greenhalgh et al., 2004, p. 601). Walker's qualitative study of US organisations that have made sustained efforts to transform found that the process was unique to each organisation, with one director stating that it was "emergent through interactions of individuals, context, finance, politics" (Walker, 2012, p. 409).

10.13 To consider possible reasons for the organic and messy nature of organisational change, the structures and processes in organisations delivering human services need to be considered.

UNDERSTANDING HUMAN SERVICE ORGANISATIONS

10.14 Organisations are often portrayed as top-down hierarchies in which leadership and management, directed by policy goals, determine people's activities on the ground. In reality,

however, it is often the everyday, on-the-ground, small-scale interactions that determine an organisation's effectiveness and outcomes (Garrow & Hasenfeld 2010; Hughes & Wearing, 2013). An example of this was seen in section 4.27, where staff in a community group home for people with intellectual disabilities undermined the organisation's aims by ignoring inclusive policy, engaging in 'othering' of the people they were supporting, and prioritising staff preferences over those of supported people (Bigby et al., 2012).

10.15   For this reason, human service organisations are better seen not as hierarchies but as interconnecting facets of practices (Hughes & Wearing, 2013). Goals, policy and funding, or *macro* practices, are decided by senior figures, leaders, or government. *Mezzo* practices are typically determined by managers; they include systems and processes such as training, staff conditions and recruitment (and are essential to the organisation's functioning, though often experienced by staff as managerial impositions). *Micro* practices are person-to-person daily interactions within organisations that take place between staff as well as staff-to-client and client-to-client; individuals' decisions regarding these interactions shape organisations daily.

10.16   Policymakers should always seek feedback on how macro policies are enacted in practice at mezzo and micro facets of organisations (Hughes & Wearing, 2013). For example, people working in different roles in an organisation may have different views of the goals and priorities of intellectual disability services (Jenaro, Vega, Flores, & Cruz, 2013). Jenaro and colleagues found that professionals, direct support staff and managers in intellectual disabilities services in Chile differed in their views of essential supports; for example, managers and professionals considered self-determination to be a key element of quality of life but direct support staff rarely mentioned it and did not mention dimensions such as social inclusion or rights.

10.17   In addition to these interconnecting facets of organisations, there are other, less visible features. Culture, metaphors, and emotions, often unarticulated or even unconscious, exert a powerful influence on people's expectations and behaviours in an organisation.

10.18   It may seem puzzling to include metaphors as a factor affecting an organisations functioning. However, researchers on change in human services note that the widespread use of machine-like metaphors to refer to human service organisations creates the impression of entities with predictable, easily quantifiable, 'inputs' and 'outputs'. In turn this leads to expectations that professionals, direct care staff, even people receiving services and their families, will function as efficient, predictable cogs in the machine. As humans are relational, and have needs that change with circumstance and context, such expectations are unrealistic and "profoundly unhelpful" (Kitson, 2009, p.217). Human service organisations are better viewed as networks of interpersonal relationships and meaning (Kitson, 2009; Grant, Mills, Bridgeman & Short, 2006; Hughes & Wearing, 2013; Suchman, 2001, 2011).

10.19   A further under-researched aspect of deinstitutionalisation is organisational culture: the taken-for-granted customs and practices that dictate roles, positions, behaviours and interactions within it. Individuals are socialised into the culture of an organisation. Drawn into an 'implicit psychological contract' and discouraged from breaking unspoken rules, they develop mind-sets and ways of behaving that lead them to prioritise prevailing practices and resist new approaches (Fineman, 2003; Grant et al., 2006).

10.20   In addition to metaphors and culture, emotions are a neglected concept in the organisational literature (Hughes & Wearing, 2013). Emotions are important because they affect information processing, influencing sense-making in times of uncertainty and affecting how staff interpret change (Klarner, Todnem By & Diefenbach, 2011), and as will be seen below, emotions play an important role in resistance to change.

10.21   The roles of leadership, staff, organisational culture and emotions in organisational change are discussed further in subsequent sections.

ORGANISATIONAL CULTURE

Normative behaviour expectations in an organisation form the context in which individuals and teams are embedded.

(Denti & Hemlin, 2012, p.8).

'How things are done around here'. It is what is typical of the organisation, the habits, the prevailing attitudes, the grown up pattern of accepted and expected behaviour.

Drenna (1992, as cited in Gillett & Stenfert-Kroese, 2003). This definition was used for the Moving Ahead project focus groups (Linehan et al., 2014b)

10.22   Organisational culture is thought to have a profound influence on deinstitutionalisation, but is under-researched (Felce et al., 2007; Walsh et al., 2010). The culture of an organisation is expressed in multiple ways: in assumptions and attitudes of managers and staff (explicit or implicit); and in manager and staff practices. Similar to the structure of organisations, their culture is not created in a hierarchical process from power holders' values through staff attitudes and practices; rather, it most likely results from complex interactions of external and internal factors such as leadership commitment; power, structures and control systems; formal policies and processes; and informal stories, rituals and routines (Alvesson, 2002; Bigby et al., 2012; Johnson & Scholes, 2002).

10.23   Gillett and Stenfert-Kroese (2003) found that community group homes for people with intellectual disabilities provided better dignity, choice, relationships and community access if they had a more positive organisational culture, and lower competitive, perfectionist and oppositional orientations. The authors conclude that "there may well be a meaningful relationship between organisational culture and quality outcomes although the nature of this relationship is far from clear" (p.279).

10.24   In poorly performing group homes in Australia (Bigby et al., 2012), described in section 4.27 of this report, the culture was dominated by a staff clique who were opposed to the values of the organisation and to national policy, and who engaged in institutional-like practices in their interactions with the people they were supporting. In this way, institutional habits may transfer to the community (Overkamp, 2002; Van Alphen et al., 2009). It is therefore critical that organisations achieve a paradigm shift for themselves and for their staff, moving from a culture of 'caring for' clients to one that both explicitly and implicitly aims to 'support' them (Schalock & Verdugo, 2012). This involves change and innovation by leaders, and staff understanding of the need for change and agreement to participate in it.

10.25   There is strong direct evidence that clear strategic vision supports the process of change (Greenhalgh et al., 2004). Leaders are central to innovation, managing the organisation's strategic goals and contributing to its environment (Denti & Hemlin, 2012), and an innovative management style is associated with more successful implementation of community living for people with intellectual disabilities (Nieboer et al., 2011).

10.26   However, top-down organisational change is rarely popular with public sector employees, (Parlalis, 2011), and employee participation is required for successful change. When closing an intellectual disability institution, managers should introduce new cultural behaviours, pass on new skills and values to staff, and be seen to adopt the practices they preach (Parlalis, 2011). Managers should not rely on accident to produce results but rather should specify the staff activity that produces outcomes desired by people with intellectual disability and their advocates (Mansell et al., 1994).

10.27   To implement change, organisations need leaders that value knowledge sharing, both outside the organisation as well as within it. Organisations also need to have good existing knowledge and skills, as well as a 'learning organisation' orientation, so that leaders, managers and staff develop a strong ability to identify, interpret and reframe new knowledge; to link it to their existing knowledge and to implement it (Greenhalgh et al., 2004). Intellectual disability organisations in the process of change have successfully drawn on learning communities to share strategies, resources and problem-solving as well as positive energy; successful learning communities can function as a organisational 'lifeline' (Walker, 2012).

10.28   In addition, it is important to note that managerial change strategies often focus on employee compliance, yet barriers to change may in fact lie with managers themselves. In discussing social work practice, Hughes and Wearing (2013) cite managerial factors that impeded effective change in financial services:

1.   Poor communication with staff: little or contradictory information
2.   Process of change too fast or too slow: unrealistic expectations or poor sequencing
3.   Poor relationships: managers were remote or autocratic
4.   Lack of consultation: employee ideas were ignored
5.   Change leaders lacked credibility, skills, experience in employees' eyes
6.   Senior management did not participate in all aspects of change programme

10.29   Some studies of change focus on these various leadership and managerial elements. However, others focus more on staff practices (Emerson & Hatton, 2005). What staff actually do, and how they think about their role, may not be in line with an organisation's formal aims, structures, and processes (Bigby et al., 2012; Felce et al., 2002), hampering the implementation of change.

STAFF FACTORS

10.30   Staff attitudes and responses are key to organisational change. This is particularly the case in intellectual disability services, where staff turnover is a major concern, bringing serious consequences for services such as poor continuity and inexperienced staff (Hatton et al, 2001; McConkey, 2000)

10.31   When implementing innovations in disability and other human service organisations, staff do not simply adopt changes. Instead, they interact purposefully and creatively with them: they

"experiment with them, evaluate them, find (or fail to find) meaning in them, develop feelings (positive or negative) about them, challenge them, worry about them, complain about them, 'work around' them, gain experience with them, modify them to fit particular tasks, and try to improve or redesign them—often through dialogue with other users" (Greenhalgh et al., 2004, p.598).

10.32   Staff vary in their perceptions of the worth of a change and in their capacity to adapt to it (Greenhalgh et al., 2004); their responses to innovation are affected by :

- *Individual traits and abilities:* individual traits such as tolerance of ambiguity, intellectual ability, motivation, values, and learning style
- *Motivation and needs:* If motivation (values, goals) coincide with staff skills and needs, adoption of an innovation by them is more likely
- *Meaning:* The meaning attached to innovation has a powerful influence; adoption is more likely if this meaning matches meaning for management, service users, and other stakeholders. Meanings can be negotiated and changed, e.g., by discourse within the organisation or across inter-organisational networks
- *The role of others:* Staff responses to innovations may take one of several forms: they may be *contingent* on decisions made by others in the organisation; *collective*, where the group decides; or *authoritative* where they are instructed to adopt it. However, although compulsory adoption may be successful at first, it may reduce successful routinisation.

10.33   Staff are not necessarily innately resistant to change. Rather, they may fear "loss of status, loss of pay or loss of comfort" (Dent & Goldberg, 1999, p. 26). Such fears are valid in the case of deinstitutionalisation, as many staff providing community supports for people with intellectual disabilities will need to be more flexible, to work alone more often, and to work on shift patterns that are less clear. This has potential implications for job-related satisfaction, stress, and turnover, issues that require investigation (Felce et al., 2008; Hatton et al., 2001).

10.34   Greenhalgh et al. (2004) note that staff who will be adopting a new way of working need particular kinds of information, at three stages of implementing change:

1. *Preparation:* Staff need to be aware of the innovation; have sufficient information about what it does and how to use it; and should have clarity about how it will affect them personally, for example, in terms of costs
2. *Early Stages:* Staff need information about what the innovation does and sufficient training and support on task issues (i.e., about fitting the innovation to daily work)
3. *Established Use:* Staff need adequate feedback about consequences of adoption and opportunity, autonomy, and support to adapt and refine.

They also note that centrally developed change is more successful if staff perspectives are incorporated during development. This should include developing shared understandings of the meaning and value of the change, and a shared language for describing it (Greenhalgh et al., 2004).

10.35   In change management workshops for UK human services, Jones (2000) found that staff sought to maintain their integrity in the face of change, but that their strategies for doing so varied depending on their attitudes to the change:

- *Engagement*: Staff were committed to innovation, learning, and adopting new values
- *Overt compliance with private resistance*: Staff maintained their own sense of integrity by not being drawn into complete collusion with a new system

- *Withdrawal*: Staff maintained integrity by overtly resisting change, through long absences based on sick leave, burn-out or despair

10.36 Finally, the success of organisational change can be affected by staff job satisfaction and turnover. These depend on factors such as conditions and wages, and on organisational characteristics, management style, staff characteristics (e.g. commitment, stress, autonomy) and client characteristics (e.g. support needs) (Buntinx, 2008). In the Netherlands, Buntinx found that factors that contributed to intellectual disability team effectiveness were job satisfaction, role clarity, employee self-efficacy and autonomy. If the team remained together for more than 12 months, overall team efficacy and output was greater; the length of staff service with a team appeared to be the strongest predictor of perceived support quality by people with intellectual disabilities.

10.37 Frequently, even where it is clear that current services are not workable, people may block reform if it threatens deep-seated institutional features and long-standing ways of life, or if it challenges widespread beliefs, for example about people's nature and abilities (Sabel & Zeitlin, 2012).

10.38 Beliefs, values and mental models are particularly difficult to change. They may be about organisations ('things can't change') or about people with intellectual disabilities ('they can't learn something new') (Grant et al., 2006; Hughes & Wearing, 2013; Nieboer et al, 2011; Schalock & Verdugo, 2012). An example was noted in section 7.25 where, despite staff beliefs in full inclusion, they had an attitude that greater inclusion was 'not realistic' for people with more severe disabilities (Bigby et al., 2009).

10.39 Schalock and Verdugo, in a leadership guide for change in intellectual disability organisations, argue it is essential to "identify and understand these mental models… and recognise that they frequently represent the limiting factor to organisation change" (2012, p.6). There is strong empirical evidence that "convergent thinking and routines … are the norm in large, well-established organisations", and that leaders are "especially helpful in encouraging organisational members to break out" of these (Greenhalgh et al., 2004 p. 607). A leader's first task is replacing 'historical' mental models, such as a disability model based on "defectology", with "future-oriente'" ones, such as a social model of disability (Schalock & Verdugo, 2012, p. 7).

10.40 At times of change, more positive emotions are found in organisations where individuals have greater control over aspects of the change process such as its speed, frequency and timing (Smollan et al., 2010). To keep distressing feelings and thoughts about change at bay, employees may resist it with behavioural, cognitive and emotional strategies (Grant et al., 2006; Young 1990). For example, anticipating loss, a coping strategy of resisting change may be employed, "to preserve what was valuable in the past" (Antonacopoulou & Gabriel, 2001, p. 446). It may therefore be helpful to employ cognitive and psychodynamic perspectives to understand underlying psychological processes affecting change (Hughes & Wearing, 2013).

10.41 It is important to note that emotions may be mixed. Staff may, for example, fear redundancies or loss of working hours, but also hope for improved outcomes for people with disabilities. Klarner et al. (2011) suggest that organisational researchers therefore need a more nuanced approach to examining employees' event appraisals and emotions at times of change: "We lack sufficient knowledge of how change triggers different emotions within an individual and how, in turn, such emotions lead to different employee coping strategies" (p. 334).

10.42   Schalock and Verdugo (2012) suggest leaders can support change by focusing on positive emotions such as hope rather than negative ones such as fear, and by using "future language" (p. 162). They also propose that leaders can overcome staff resistance to change in intellectual disability organisations by changing historical mental models; reassuring staff about their futures; clarifying the organisation's future vision; engaging in values training; creating incentives to work in new ways; and using demonstration projects to show change is possible and realistic. Schalock and Verdugo recommend developing positive views of the organisation as future-oriented, open, creative and risk-taking, and pacing change to allow for questions, absorption, and variations in staff receptivity.

SUMMARY: THE ROLE OF ORGANISATIONAL FACTORS

10.43   Change in large human service organisations is complex and is determined by interactions with the local context and those who are adopting it. Contextual external factors, such as policy, government officials, and funding allocations, may influence the success of change. Many organisational factors are also likely to influence the deinstitutionalisation process, such as the organisation's culture including attitudes to change; leadership ability to change existing mental models; management clarity, coherence, strategy and support style; support for professionals; rewards for staff input; and staff skill. Changes need to take place at every level of an organisation, so that macro aims are practiced at the micro level. Achieving change from facility-based services to more individualised supports in intellectual disability organisations is an ongoing process that needs to be adapted to every organisation and that requires perseverance and commitment.

11. Supporting Life in the Community (V): Creating Quality, Accountable Services

"Dynamic accountability" versus *"rules and furtive discretion"*

(Sabel & Zeitlin, 2012)

11.1   Recent reviews of disability services in Ireland, such as the Comptroller and Auditor General's report on Provision of Disability Services by Nonprofit Organisations (2005) and the Value for Money and Policy Review of Disability Services (Department of Health, 2012) note that there has been a consistent failure, by both the Health Boards/HSE and voluntary service providers funded by the state, to account for spending and services delivered in the disability sector. Noting that many services have failed to be audited, some of which are receiving millions of euros in state funding annually, the reports call for robust accountability procedures to be implemented. These reports are summarised in the policy review that partners this scoping review (Linehan et al., 2014a). Here, we briefly address the critical issue of accountability in services for people with intellectual disability in Ireland. We consider international theory and practice in human services governance, before turning to approaches to evaluation.

11.2   The urgent need for accountability in disability services in Ireland is undisputed. The Value for Money and Policy Review of Disability Services (Department of Health, 2012) called for the comprehensive implementation of Service Level Agreements between the HSE, as disability services commissioner, and the voluntary agencies providing such services. These should contain clear, detailed and specific performance indicators, with ongoing service monitoring and compliance reviews. The approach taken echoes the development in recent decades in wealthier economies of the 'new public management' (NPM) of public services (Organization for Economic Co-operation and Development [OECD] 1995).

11.3   NPM is based on a critique of public services as being high-cost, poor quality and poor accountability (Cumella, 2008; Marsh & Spies-Butcher, 2009). NPM aims to achieve quality services, practice innovation, and cost control, by introducing market approaches to human services, applying market principles of efficiency, financial management and consumer choice (Cumella, 2008; Marsh & Spies-Butcher, 2009; Power & Kenny, 2011).

11.4   NPM focuses on efficiency (the cheapest means of achieving specified goals). Efficiency is sought by specifying roles and outcomes in advance, and with competitive tendering; performance management systems with highly specified targets; rewards for compliance; and increased central control. Management relationships with professionals are construed as business transactions with specified outputs, often referred to as Key Performance Indicators or KPIs (Marsh & Spies-Butcher, 2009; Tossebro et al., 2012).

11.5   Despite NPM's goal of improving poor public services, there are concerns about its ability to do so, with "vigorous critiques" (Cumella, 2008, p. 180) suggesting that NPM diverts funding from the public to private sector, providing services that are not cost-effective, with illusory choice, loss of accountability, and poorly co-ordinated, target-chasing approaches in services (Cumella, 2008). A number of features of NPM contribute to this: competition may impede co-operation and innovation; isolated, short-term outputs encourage adversarial management rather than co-operation for long-term gain; service commissioners' and recipients' requirements change over time, so specifying detailed outcomes in advance and using competitive tendering may in fact prove less efficient; and there is less room for professionals and advocacy groups to be involved in developing policy goals (American Public Health Services Association [APHSA], 2013; Marsh & Spies-Butcher, 2009; Tossebro et al., 2012). An example of a limitation of NPM in intellectual disability services is that changing or rotating staff achieves greater efficiency, but that this creates a less effective service as it reduces the quality of staff-client interactions (Buntinx, 2008).

11.6   Critics also note, importantly, that although assumptions are made that NPM generates greater efficiency, governments have been reluctant to evaluate the impact of reforms, including in intellectual disabilities services in England, where NPM reforms were introduced following the 2002 *Valuing People* white paper (Cumella, 2008).

11.7   A market-led, tightly specified managerialist NPM climate may not be helpful in human service organisations. There are warnings from several countries that the 'logic of management' is becoming more dominant than the 'logic of relationships' between staff and supported people (Buntinx, 2008) in intellectual disability services, as human services become increasingly managerialist and focused on specified outputs, efficiency and compliance (Tossebro et al., 2012). In fact human services are more adaptable, more able to communicate with one another, and perform better if their management systems allow them to be open, responsive

and to learn from mistakes. Ideally, staff and managers should be "empowered to be …
creative, critical and self-aware in their organisational practice" (Hughes & Wearing, 2013, p.
73) but this is currently rare in NPM systems. This may be a particular concern in intellectual
disability services, where moving to supported living requires a flexible, co-operative
approach to working, rather than a highly controlled and determined one (Walker, 2012).

11.8   These difficulties suggest that to achieve accountability, quality and value for money, an
        NPM-style approach may not be the optimal model of governance for intellectual disabilities
        services in Ireland. It may be worth considering the possibilities of an alternative form of
        governance: 'experimentalist' or 'pragmatist' systems. These have been proposed by
        commentators in Australia and the UK as preferable for disability services (Marsh & Spies-
        Butcher, 2009; Power & Kenny, 2011). They have yielded promising results in particularly
        challenged human services where structural obstacles seem most daunting, such as
        education, child welfare, and anti-discrimination (Sabel & Zeitlin 2012).

SEEKING QUALITY AND ACCOUNTABILITY IN COMPLEX HUMAN SERVICES (II): EXPERIMENTALIST GOVERNANCE

11.9   'Experimentalist' governance has proved effective where there are deep-rooted barriers to
        change, and it is considered ideal for systems with broad service goals, such as 'child safety'
        (Sabel & Zeitlin 2012). It may therefore be well suited to intellectual disability services, where
        goals such as 'supported living with inclusion' are broad and need to be adapted to abilities
        and circumstances of each individual, and where barriers to change continue to exist.

11.10   Experimentalist governance is reported to have been applied successfully to human services
        reform in the US in particular, yielding substantial improvements in child welfare in Alabama
        and Utah (Noonan, Sabel & Simon, 2009) and in public education in multiple US states, with
        children's reading and mathematics performance in the most deprived communities rivalling
        that of the most wealthy (Liebman & Sabel, 2003-4). In Chicago, changes to community
        policing are reported to have improved local conditions (Ansell, 2011). Experimentalist
        governance has also achieved considerable success with learning difficulties in the Finnish
        education system (Sabel, Saxenian, Miettinen, Kristensen, & Hautamäki, 2010).

11.11   Experimentalist governance takes the position that effective services must adapt to individual
        or local needs, and that frontline issues, inherently complex and ambiguous, need
        interdisciplinary assessment and solutions and flexible responses. Therefore, implementation
        and action frameworks are provisional, with regular reviews and goal revision, so that
        iterations result in change (Sabel & Zeitlin 2012). It therefore differs from conventional
        hierarchical governance and from contemporary reform movements that aim to strengthen
        relations between commissioners and service providers such as NPM (Sabel & Zeitlin 2012).

11.12   There are several key features of experimentalist governance. Efficiency is not viewed as the
        cheapest route to specified outcomes, but rather as achieving effective solutions for complex,
        changing environments. In addition, a learning orientation, rather than a hierarchical one,
        characterises commissioner/agency relationships, with a process of 'dynamic accountability'
        replacing the all-too common combination of "rules and furtive discretion" (Sabel & Zeitlin
        2012, p. 174). This produces a new set of relationships between the 'centre' (e.g. a regional
        entity or a service), and its 'local' units, for example frontline workers such as teachers or
        social welfare workers. Together, in an iterative process, they set and revise goals and the
        means of pursuing them (Sabel & Zeitlin 2012).

11.13   As knowledge is considered provisional, collaborative learning is key. Informal pressure to
        perform well is encouraged by group decision-making and by the routine dissemination of

performance information, with indicators based on provider and client experience. Issues are scrutinised from diverse perspectives; for example, perspectives of the family, as well as heath, legal, therapeutic and educational systems are combined in child protection under experimentalist governance (Noonan et al., 2009; Sabel & Zeitlin 2012).

11.14   Implications for human services of an experimentalist governance approach are therefore:
- Goals are provisional, and adjusted in light of new knowledge, with continuous monitoring, comparisons, error detection and analysis of root causes
- Accountability consists of *giving reasons* for pursuing goals, rather than just comparing performance to a specified goal or rule
- Early non-compliance triggers increased support from the oversight body, not punitive responses; but with repeated non-compliance, a unit or organisation is dissolved.

11.15   Sabel and Zeitlin (2012) note that experimentalist governance has proved effective in the face of deeply rooted structural obstacles to change. They caution that further generalisation beyond existing examples remains to be demonstrated. However, in various human services in different jurisdictions it has created successful reform in challenged areas of social life where none had seemed possible.

THE ROLE OF EVALUATION IN ORGANISATIONAL CHANGE

11.16   There is a long, ongoing history of poor accountability and transparency in intellectual disability services in Ireland (Linehan et al., 2014a; Quinn, 2014). Internationally, evaluation and accountability mechanisms are less evident in nonprofit organisations (Fleishman, 1999; Hayes, 1996; Herzlinger, 1996; Kramer, 1981; Salamon, Hems, & Chinnock, 2000): for-profit businesses are accountable to consumers and boards of directors, and government is considered accountable through the democratic process. Issues of senior executive remuneration (not disclosed by charities in Ireland), other advantages accruing, and the "ad minimus approach to financial reporting" by charities in Ireland (Quinn, 2014) has been under recent political scrutiny by the Public Accounts Committee (PAC) of the Houses of the Oireachtas (Irish Parliament), whose Chairman called in 2014 for the "veil of secrecy surrounding some charitable organisations [to be] pulled aside immediately and the opacity of their accounts and other contractual and professional arrangements [to be] removed once and for all" (Houses of the Oireachtas, nd).

11.17   Whatever the governance approach adopted, there is international agreement that transparency and evaluation are critical for creating high quality, accountable intellectual disability services (Hughes & Wearing, 2013; Moxley & Manela, 2000). Evaluation is increasingly included as the final stage of change in complex human service organisations. It can be proactive, assisting an organisation to define and assess goals and activities to better meet recipients', funders', and regulators' expectations. It can be protective at times of crisis, assisting with renewal of purpose and operations. However, evaluation must be meaningful, providing systematic data from multiple stakeholder perspectives, that can advance the agency's practice (Hughes & Wearing, 2013; Moxley & Manela, 2000).

Evaluation in NPM and experimentalist approaches:

11.18   NPM systems generate numerous and exacting mandates with highly detailed specification of norms, goals, targets and outputs and an extensive regime of auditing and quality control (APHSA, 2013). These have the benefit of creating transparent accountability systems, and

may therefore be particularly apposite for the Irish context where there has been little oversight of service provision for many decades.

11.19   However, there are also disadvantages to such an approach in human services. With a focus on specifying service components in advance, and measuring 'inputs' and 'outputs', NPM has a machine-like conceptualisation of services, and may thus promote inflexible or unrealisable expectations in leaders and managers (see section 10.18 above). Commentators note that human and public services typically benefit from allowing flexibility for on-the-ground staff, managers and leaders to innovate and reflect on their practice, and that outcome assessment benefits from a longer-term lens (APHSA, 2013; Hughes & Wearing, 2013).

11.20   Experimentalist/pragmatist forms of governance rely on a routine 'diagnostic monitoring' process called Quality Service Review (QSR), which monitors compliance to norms while continuously reconsidering them (Dorf and Sabel 1998; Noonan, Sabel & Simon 2009; Sabel & Zeitlin 2012). Rather than checking compliance with pre-set norms and rewarding or punishing accordingly, a two-person team (one from within the agency and one from outside) engages in detailed file reviews of a stratified random sample of cases, and conducts interviews with all stakeholders (child, family, other caregivers, professionals, etc). Cases are scored in multiple domains; scoring is refined through meetings with caseworkers and supervisors, and any recurring problems identified (Sabel & Zeitlin 2012), to identify systemic problems. Scores can be compared over time and cross-regionally (Sabel & Zeitlin 2012).

SUMMARY: ACCOUNTABILITY AND EVALUATION

11.21   NPM and experimentalist governance represent contrasting methods of achieving quality services in human services. Both stress the importance of evaluation and compliance but take a different view of how this is best achieved. NPM approaches make the expectations of service commissioners very clear, and generate explicit metrics by which these can be assessed. However, they have the disadvantage of inflexibility, which may lead to poor service provision. Experimentalist approaches are more subtle and flexible but require more active involvement in assessment. Both governance approaches require greater evaluation themselves.

12. Barriers and Facilitators to Deinstitutionalisation: Lessons from Irish and European Evaluations.

Policies without funding commitments and plans without resources are nothing more than delusional optimism or political hot air.

(Mansell et al., 2007, p.52)

In Ireland, "the rhetoric does not match the reality. There is a vision, but no clear direction, leadership or mandate"

(Townsley, Ward, Abbott, & Williams, 2010)

12.1   To achieve quality deinstitutionalised services, changes are needed to housing, but also to organisational structures and leadership, staff training and attitudes, and community services. In addition, the attitudes and preferences of people with intellectual disabilities and their families need to be considered.

12.2   Ireland's nationwide deinstitutionalisation programme lags behind many European countries. Valuable lessons are provided by three recent seminal sources that examine the reconfiguration of disability services across Europe and in Ireland, highlighting key barriers and facilitators of the process (Table 4). They are (i) the DECLOC study estimating numbers of people with disabilities in institutions in Europe and proposing a pathway for moving to community living (Mansell et al., 2007); (ii) a synthesis of policies on independent living for people with disabilities in Europe by Dr Ruth Townsley and colleagues for the Academic Network of European Disability Experts (ANED[3]) (Townsley, Ward, Abbott, & Williams, 2010); and (iii) an Irish evaluation of demonstration projects for moving to more personalised, community living (McConkey, Bunting, et al., 2013).

Table 4: Three recent seminal reports examining reconfiguration of disability services in Europe and Ireland

Study	Paper
Deinstitutionalisation and Community Living: Outcomes and Costs (DECLOC)	Mansell, J., Knapp, M., Beadle-Brown, J., & Beecham, J. (2007). *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Vol. 2: Main Report*. Canterbury: Tizard Centre, University of Kent.
European policies supporting independent living for people with disabilities in Europe: Academic Network of European Disability Experts (ANED)	Townsley, R., Ward, L., Abbott, D., & Williams, V. (2010). *Implementation of policies supporting independent living for disabled people in Europe: Synthesis report, Academy Network of European Disability Experts (ANED).* Bristol: Norah Fry Research Centre
Irish evaluation of demonstration projects for moving from congregated settings to more personalised, community living	McConkey, R., Bunting, B., Ferry, F., Garcia-Iriarte, E., & Stevens, R. (2013). *An evaluation of personalised supports to individuals with disabilities and mental health difficulties.* University of Ulster and Genio.

IRELAND ON THE EUROPEAN CONTINUUM TOWARDS DEINSTITUTIONALISATION

12.3   Ireland's progress towards deinstitutionalisation can be set in a European context with the findings of the DECLOC report (Mansell et al., 2007). This report defined a continuum of deinstitutionalisation to independent living options across Europe, specifying three steps:

> 1-   *Transforming and reforming institutional care*, characterised by separation of buildings and support in service provision

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[3] *The Academic Network of European Disability experts (ANED) was established by the European Commission (EU) in 2008. Its purpose is to provide scientific support and advice for the Commission's Disability Policy Unit; in particular, to support the future development of the Disability Action Plan and practical implementation of the United Nations Convention on the Rights of Disabled People.*

2- *Community living*, which requires evidence of providing options and support in the community

3- *Independent living*, which requires evidence of support for people to live in their own homes and have choice and control through independent budgets.

12.4   The ANED report (Townsley et al., 2010) places Ireland midway between Steps 1 and 2 of this process, because community-based options have been developed. However, it should be noted that in fact Step 1, the separation of buildings and support, has yet be realised for most people with intellectual disabilities in Ireland.

12.5   In all jurisdictions, overarching facilitators of deinstitutionalisation are international declarations, treaties and conventions. The Universal Declaration of Human Rights and the European Convention on Human Rights entitle all individuals to basic human rights such as liberty, dignity, and autonomy. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) specifically applies many of these rights to individuals with disabilities. In relational to living arrangements, Article 19 of the UNCRPD calls for people with disabilities to be afforded their choice of both where and with whom they live, noting that they are not obliged to live in any particular setting. The UNCRPD also calls for community supports that are responsive to their needs.

12.6   Internationally, implementation of the conventions is, at best, variable, and certain practices in institutions throughout Europe are clearly in breach. Although there is little recourse against non-compliance, international policies provide an important context for establishing national policies and a starting point for deinstitutionalisation. At the time of publication, Ireland has signed but not ratified the UNCRPD.

12.7   Recently there has been what might be termed an explosion of national disability policies in Ireland, with six published since 2011. These are summarised in the policy review accompanying this report (Linehan et al., 2014a). Culminating in a highly influential Value for Money and Policy Review of Disability Services commissioned by the Department of Health (2012), these policies present a consistent picture: Ireland must reconfigure disability services, moving from a system of block funding of large statutory and non-governmental service providers to a more personalised system affording choice and control, including financial control, to people with disabilities. Furthermore, services must become more accountable, with provision specified in detail and monitored for compliance.

12.8   While the goal of quality, accountable, community provision is reasonably clear, across Europe the process of implementation and the degree of success are less clear. The ANED report, examining implementation of independent living for people with disabilities in 25 European countries, provides strong evidence that few are even close to matching service provision to their strategic commitments (Townsley et al., 2010). Mansell et al. (2007) also noted that Germany, England and Italy faced difficulties in implementing national plans. Siska and Beadle-Brown (2011) have more recently outlined similarly challenges in moving to community services in the Czech Republic.

12.9   Common challenges include local resource limitations, regional differences in interpreting national policy, and lack of leadership (Townsley et al., 2010). A complex process, it cannot be left to local services: "It is simply not feasible to leave to the institution, or the local authorities involved, the task of dismantling institutions which serve people from many different municipalities" (Mansell et al., 2007, p.95); regional and national agents must be

involved. Poor implementation is also found in Ireland, where "the rhetoric does not match the reality. There is a vision, but no clear direction, leadership or mandate to put this [strategic commitment] into practice at local level" (Townsley et al., 2010, p.16).

12.10　Some overlap in quality outcomes across living arrangement models, including inconsistent findings on outcomes for different types of community settings, may be interpreted as evidence that 'better' large institutions can produce quality outcomes comparable to 'weaker', smaller institutions, which in turn can achieve quality outcomes comparable to community-based housing. As Mansell, Beadle-Brown and Clegg (2004) note, however, these conclusions are unfounded; detailed inspection of these findings favours community settings.

12.11　In the midst of the many challenges that present as disability services reconfigure from congregated to individualised supports, the focus on the individual, staff, and broader local community may have diminished the significant barrier of accessing housing itself. Deinstitutionalisation is also a major re-housing process which requires sourcing multiple dwellings that are appropriate and within budget (Bostock, Gleeson, McPherson, & Pang, 2004).

THE DRIFT BACK TO INSTITUTIONS: THE 'ECONOMIC ARGUMENT'

12.12　In the process of deinstitutionalisation, vigilance is required. Several European countries with laudable national deinstitutionalisation policies and practice are now engaging in retrograde steps. National experts in Germany, the Netherlands and Slovakia, for example, all reported to ANED that the number of people supported in institutions was increasing (Townsley et al., 2010). A trend towards introducing new community-based institutions is also seen in Norway, once the "most outstanding" example of Scandinavian deinstitutionalisation, where national government policies for community living now "evaporate on their way to implementation" (Tossebro et al., 2012, p. 141). Community group homes have doubled in size, supporting a mean of 3.8 people in 1994 to 8.1 in 2010, and over half of people with intellectual disability now live with seven or more others. Denmark, Finland and Sweden are following suit (Tossebro et al., 2012). The pattern is also emerging in the UK (Mansell, 2007).

12.13　This relapse into congregated provision sends a warning to all jurisdictions. Even where community living has been accepted in principle, is well grounded in legislation and policy, and has been widely implemented, congregated settings may re-emerge. Governance and tax approaches may contribute to these developments. In Scandinavian countries, the introduction of NPM, with its focus on managerialism and efficiency, has led to service restructuring and demands for financial compliance (Tossebro et al., 2012). A 2009 Academic Network of European Disability experts (ANED) report noted that in Ireland, tax incentives of up to 40% were available to those investing in private hospitals and registered care homes, and that many congregated facilities built on the basis of this financial incentive remain operational and people continue to be placed in them (Centre for Disability, Law & Policy NUIG, and ANED, 2009). Vigilance is required to ensure that these perverse incentives do not undo the considerable efforts of deinstitutionalisation.

12.14　As noted in section 5, the 'economic argument' is a key barrier to developing community services. The ANED report identifies a perception in many jurisdictions that the cost of supporting individuals appropriately in independent living is prohibitive, particularly during economic recession; economies of scale arguments suggest that the cost of provision decreases as the number of individuals in a setting increases (Townsley et al., 2010).

However, this perspective fails to consider the quality of the support, as the DECLOC report notes (Mansell et al., 2007).

12.15 An additional barrier is the complexity of funding streams. Mansell et al. (2007) identify several common funding routes in disability services. Central funding is present where providers receive funding from a central source, typically the state, commonly based on a performance related agreement. An alternative is commissioning: providers engage in a competitive tendering process. It is debatable whether competitive processes benefit those receiving services (Marsh & Spies-Butcher, 2009). The benefits of greater choice may be realised at the cost of a lack of inter-agency co-operation.

12.16 More complex issues arise where block funding budgets awarded to institutions are diverted to a funding stream that is disaggregated through multiple providers such as social care, housing and health. Joint commissioning across services may present considerable challenges in dividing costs between providers. This becomes more complex where individualised budgets, based on individual support needs, are allocated to individuals to commission their own personalised supports. Mansell et al. (2007) argue that policy makers need to coordinate these funding streams to ensure that a seamless structure is in place to facilitate them.

12.17 The need for coordination extends further. As individuals move to the community, they will access multiple facilities and services provided by public bodies, voluntary agencies and private providers. In addition to multiple funding streams, these bodies may have varying eligibility criteria and the organisational ethos may differ. Policy makers need to consider how these can best be coordinated.

12.18 Local planning is key to ensuring a smooth transition from institutional to community provision. 'Archetypal' institutions are unlikely to realise funds when sold, as they are often located in isolated settings and in a state of poor repair. However, Mansell and colleagues (2007) suggest that any funds realised from deinstitutionalisation should be ring-fenced to fund community services for those formerly resident in institutions. They note that local plans for closing large facilities require specified and realistic timeframes; transfer of funds from health to community budgets; staff redeployment; plans for developing community supports; realising capital from institutional property and lands; and clear consultation with all stakeholders, particularly people with disabilities.

PLANNING FOR CLOSURE: CONSIDERING STAKEHOLDER VIEWS

12.19 Any consultation with stakeholders must consider their preferences. As Mansell et al. (2007) note, these may represent both barriers and facilitators to change. People with disabilities may be reluctant to leave the familiarity of life in an institution. However, in time, most prefer their new life in the community. Families also express reservations, fearing hostile reactions in the community such as bullying and isolation (Townsley et al., 2010). McConkey, Bunting et al. (2013) note that these concerns may be perceived as irrational; however, they report that staff who were honest with families and gained their trust were able to allay these concerns. Preferably, new approaches should be developed, where people with disabilities and their advocates work to develop services in partnership with disability organisations (Mansell et al., 2007).

12.20 Family concerns may fuel interest in 'trans-institutionalisation', that is, moving to alternative congregated settings such as village communities and secure placements where interactions with local communities are minimised (Mansell et al., 2007). These settings may also be

preferred by the wider community where understanding of disability may be limited and where concerns about 'dangerous' behaviours by people with disabilities do little to foster community inclusion.

12.21   In any local deinstitutionalisation plan, the provider organisation will play a key role. McConkey, Bunting et al. (2013) note that this is particularly the case in Ireland, where "the bulk of the resources and associated power resides almost exclusively with the service provider and therefore much of the power to change resides here also" (p.98). This study noted that a cultural shift existed in many organisations embracing change, which spurred their progress on reconfiguring services, and that policies, dedicated teams and leadership promoted changes towards deinstitutionalisation.

12.22   An important element in any local plan for institutional closure should be flexibility: the ability to change and adapt depending on progress. Mansell et al. (2007) cite the example of institutional closure at Darenth Park in the United Kingdom. The original plan included the option of smaller congregated settings; however, this was halted when the success of those who moved to dispersed housing in the community was reviewed.

12.23   Evaluation data from the early stages of deinstitutionalisation in Ireland suggests that flexibility and reflection on progress would be beneficial (McConkey, Bunting et al., 2013), echoing the goals and approaches of experimentalist governance outlined in Section 11.19 (Sabel & Zeitlin, 2012). Despite policy directives proposing that people in congregated settings move to independent living, demonstration projects reveal that most have moved to community group homes; only a small minority have moved to more personalised settings (tenancy arrangements with staffing as required). The authors note that although a group home may be seen as a step towards more independent living, individuals may then remain there. Flexible planning would permit a swift and targeted response to this pattern.

12.24   Local plans must also be financially costed. Plans should address the cost of leaving congregated settings as well as the costs of moving to well-prepared communities where needs are appropriately met. Mansell et al. (2007) recommend investment in new capital and staff supports before institutions are wound down and sold, to ensure they are ready for individuals moving to the community. Costings must be ring-fenced; "policies without funding commitments and plans without resources are nothing more than delusional optimism or political hot air" (Mansell et al., 2007, p.52).

12.25   Any proposed closure of large institutional facilities needs to consider the impact on the local economy. It is unlikely that all former residents of such facilities will find accommodation locally; some may repatriate to where their families live, others may prefer to move to more distant locations. In some areas, an institution may be the main employer with generations of the same family employed as staff, and the level of staffing required to support local community services is likely to be lower. Local staff who cannot be redeployed may be offered redundancy or early retirement. While community-based services may be an employment opportunity for some, strategic planning is required to source employment opportunities (Mansell et al., 2007).

12.26   As individuals with disabilities migrate to communities, local services will need to replace those once provided by institutions. Insufficient community supports are a factor impeding progress to community living (Townsley et al., 2010). The coordination of health services, for example, such as physiotherapy, speech and language therapy and podiatry, which were formerly available on site may now become the responsibility of individuals with disabilities and their families (Richmond & Savy, 2005). Access to community mental health services, in particular, has been challenging for individuals with intellectual disability (Bigby & Frawley, 2010). Consideration is required to ensure that such supports are available.

12.27   The availability of skilled staff may be a barrier to developing community living models. In many cases, staff working in congregated settings will follow the people they support into community settings. In this process, they may bring institutionalised practices of their former workplace with them. Investment in training is required to ensure institutionalised practices do not migrate to the community (Mansell et al., 2007).

12.28   The development of community-based supports should focus not only on formal supports but also on natural supports such as family and friends. Changes in family structures, increases in the numbers of women at work, and greater geographical distances between family members combine to challenge traditional family supports. Any reduction in the pool of family members may add to caregiver burden and this may affect caregivers' employment and health (Emerson, Robertson & Wood, 2004; Harrison & Wooley, 2004). Mansell et al. (2007) propose incentives to support families in their caregiving role, as "the cost of the alternative – staffed care in residential settings or intensive models of home care – is too high to contemplate" (p. 77).

12.29   Despite considerable efforts by all stakeholders to support community living, McConkey, Bunting et al. (2013) note that the move to more independent living had little impact on levels of social inclusion in the community. This may reflect the fact that people were relatively new entrants to their neighbourhoods, but may also reflect the fact that staff do not typically prioritise social inclusion as part of their role (McConkey & Collins, 2010a). It may also be that, despite decades of deinstitutionalisation, poor social inclusion reflects a key remaining prejudice against people with disabilities.

12.30   In conclusion, the Irish and international evaluations summarised here provide valuable lessons for those embarking on a programme of deinstitutionalisation. Closing large institutions and replacing them with community services is a complex process driven by multiple, often incompatible demands (Bigby & Fyffe, 2006). It requires implementation, coordination and planning from a variety of agents, and it requires resources. Even in jurisdictions where deinstitutionalisation has progressed, however, the realisation of 'ordinary housing in ordinary streets' has yet to be realised; rather, people are typically moving from large scale settings to smaller but similarly institutionalised ones (Hamlin & Oakes, 2008).

13. Regional Variation

'It is simply not feasible to leave to the institution, or the local authorities involved, the task of dismantling institutions which serve people from many different municipalities' (Mansell et al., 2007; p.95).

13.1   In intellectual disabilities research, it has been argued that a new agenda, going beyond investigating familiar issues, is needed. In addition to the under-researched area of organisational factors, another poorly understood area is regional variation in services (Walsh et al., 2010). Regional service development is an equity factor. Service provision needs to be monitored carefully, not just nationally, but also locally, if equity of access is to be achieved (McConkey, Kelly, Craig, & Mannan, 2013).

13.2   Many jurisdictions report wide regional variation in the progress of deinstitutionalisation. In the US, substantial disparities remain across states in proportions of people with intellectual disabilities who receive supports in institutional or community settings, despite court decisions and legislation (Americans with Disabilities Act 1990; US Supreme Court decision *Olmstead v. LC*, 1999). By 2000, 9 states had eliminated institutions while 12 continued to operate 23 facilities with over 500 people each. Why such variability exists remains unclear (Parish 2005).

13.3   Local factors such as leadership and advocacy may play a role. For example, in Michigan, leadership by advocates and legislators led to rapid transitions; in contrast, in Illinois, fragmented leadership, powerful parenting lobbies, unions and private providers slowed community provision (Parish, 2005). Subsequently, a "Blueprint for System Redesign in Illinois" was published in 2008 (Smith, Agosta, & Daignault, 2008); yet a 2012 update of the Blueprint by its authors (Agosta, Smith, Daignault, & Kardell, 2012) found that waitlists for services had nearly doubled; that little had changed in relation to the kinds of services offered; that much remained to be done in embedding person-centred practices; that little progress had been made in measuring outcomes; that services continued to be fragmented and under-resourced; and that Illinois remained well under the national average in investment in services. They argued that Illinois remained at a tipping point, and that policy makers could either act to move the system "from one mired in the underachieving past" – or let change stall, "leaving the state system to muddle on as before" (Agosta et al., 2012, p. i)

13.4   Regional variation is also seen in European countries. In Finland, municipalities were given autonomy to develop services, which then developed differently within different regions (Miettinen, 2012). In the UK in 1991, there were substantial variations in provision of residential services across England, Scotland and Wales, where people with disabilities living in facilities supporting 50 or more people ranged from 18% to 65%, without evidence for regional variation in prevalence or characteristics of people with intellectual disabilities. Factors affecting this may have been local authority policy, existence of large-scale institutions, and the development of independent sector provision (Emerson & Hatton, 1997).

13.5   Despite these regional disparities in many jurisdictions, the issue is rarely explored in research. Policy and practice of service providers is likely to play a major role (EIDRN, 2003), but the factors impeding and facilitating change at local levels are not understood (Mansell, 2006). There is also considerable regional variation in the transition to community supports in Ireland which, as elsewhere, is poorly understood (McConkey, Kelly et al., 2013). However, unlike in most other jurisdictions, researchers in Ireland can avail of the opportunity presented by the National Intellectual Disability Database.

NATIONAL LONGITUDINAL RESEARCH ON RESIDENTIAL SUPPORTS IN IRELAND

13.6   In Ireland, the National Intellectual Disability Database records demographic information including the living circumstances of all people with intellectual disabilities who receive or are waitlisted for state services; as this is updated annually it provides a singular opportunity to

conduct national-scale, longitudinal research on living options of people with intellectual disabilities.

13.7   The authors of the cross-European DECLOC study, which estimated the numbers of people with disabilities in institutions (Mansell et al., 2007) called for a method for measuring progress to community living; normally, international data provide snapshots of development rather than measures of progress in action. In Ireland, the existence of the NIDD allows this particular issue to be explored. Ongoing analysis of the NIDD data will provide a unique opportunity to explore progress to community living year-by-year as Ireland introduces a large-scale programme of reform of disability services mandated by policy published since 2011 (Linehan et al., 2014a).

13.8   McConkey and colleagues (Kelly & McConkey, 2012; McConkey, Kelly et al., 2013) have conducted a set 10-year longitudinal analyses of transitions to community living in the decade 1999-2009. Kelly and McConkey (2012) found that there was a marked rise in the numbers of people with intellectual disability living in community settings in Ireland in the decade to 2009, with the largest rise in community group homes, the most common form of provision in the state. They also found that more people moved from congregated to community settings than vice versa. However, the proportion of people in Ireland supported in community settings, fewer than half, still remains lower than that reported for other countries and nearly half of new admissions continue to be to congregated settings. Analysis of the most recent available NIDD data, from 2012 (Kelly, Kelly & O'Donohue, 2013), indicates that although the trend towards community living in Ireland continues, progress is slow. The proportion of adults with intellectual disabilities in Ireland supported in residential centres fell from 14.7% in 2011 (n = 2712) to 13.7% (n = 2536) in 2012; adults supported in community group homes rose from 21.9% (n = 4038) in 2011 to 22.4% (n = 4147) in 2012, as did those in independent settings, from 6.0% (n = 1110) in 2011 to 6.3% (n = 1157) in 2012.

13.9   An analysis of the living options in each of eight former health board regions in Ireland, also on 1999-2009 (McConkey, Kelly et al., 2013), found marked regional variations in the numbers of people in congregated and community settings, as well as notable regional differences in change of proportions of people supported in these settings. For example, in three of the eight regions there were small proportionate increases between 1999 and 2009in numbers of people supported in congregated settings. In contrast, in two other regions the number of people supported in congregated settings fell by over 30%.

13.10   McConkey, Kelly et al. (2013) note that historical factors are likely to underlie some differences in regional provision in Ireland, where provision was largely supplied by religious orders in locations suited to the orders, who enjoyed a great deal of autonomy (Linehan et al., 2014a; McConkey, Kelly et al., 2013; Sweeney, 2010).

13.11   However "the more intriguing question" (McConkey, Kelly et al., 2013) is why some regions see proportionately more *transitions* from congregated to community living than others. Researchers suggest that variation between service providers is likely to be a factor. They argue that attitudes and practices of service directors in different regions should be explored, particularly as the role of barriers and facilitators of change at local agency level is relatively unaddressed in research to date (Mansell, 2006; McConkey, Kelly et al., 2013).

13.12   The Moving Ahead Project (Linehan et al., 2014b) was designed to answer some of these questions. The HSE report, Time to Move on from Congregated Settings, A Strategy for Community Inclusion (HSE,), identified over 4,000 people with disabilities who still live in congregated settings in Ireland, calling for their transfer to community-based living. This would require a major reconfiguration of disability services, further underpinned by the

findings and recommendations of the subsequent Value for Money and Policy Review of the Disability Services Programme (Department of Health, 2012). Targeting two regions in Ireland with strong disparities in progress towards deinstitutionalisation, the Moving Ahead Project aimed to identify factors contributing to contrasting regional trends to progress to community living.

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Appendix

To identify literature for the rapid scoping review a number of steps were followed, as recommended by Arksey and O'Malley (2005). These steps include searching electronic databases, searching reference lists and key journals, consulting knowledge networks and relevant agencies, and consulting with stakeholders. A bibliographic search was conducted of Web of Knowledge, Scopus, and PubMed with keywords such as intellectual disability, learning disability, developmental disability, mental retardation, deinstitutionalisation, relocation, transfer, community, housing, dispersed, residential, accommodation, organisational change, service development, and service planning.

Further searches were conducted by examining reference lists of papers sourced from the web-based library searches, and hand-searching of three of the key international journals in the field: the Journal of Intellectual Disability Research, Journal of Applied Research in Intellectual Disability and Journal of Policy and Practice in Intellectual Disability. In addition, a consultation stage was included as recommended by Arksey and O'Malley (2005) to allow for policy, practitioner and user experience input from the Moving Ahead Steering Groups which comprised people with intellectual disability, family members, service providers, and academic researchers.