FROM CONGREGATED TO COMMUNITY LIVING

MOVING AHEAD

Moving Ahead:
Factors contributing to the successful transition of people with intellectual disabilities from congregated to community-based residential options in two regions in Ireland.

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Further details of the study can be found at http://socialwork-socialpolicy.tcd.ie/moving-ahead/ or by contacting Dr Christine Linehan, Principal Investigator School of Psychology, University College Dublin formerly of the School of Social Work and Social Policy, Trinity College Dublin.

Acknowledgements

This report is dedicated to Professor Jim Mansell CBE (1952-2012)

1. Background to Moving Ahead

The opening section of this report summarises key research, policy findings and outstanding issues relevant to the deinstitutionalisation of people with intellectual disabilities, to give the context and rational for the *Moving Ahead* research study. In doing so, it draws on the two partner reviews completed by *Moving Ahead*. A policy review, *Mapping the National Disability Landscape* (Linehan et al., 2014) outlines current disability services and policies in Ireland[1]. A research scoping review, *Living Arrangement Options for People with Intellectual Disability: A Scoping Review* (Tatlow-Golden et al., 2014) summarises the large body of national and international research on deinstitutionalisation and community living for people with intellectual disabilities[2]. Readers are referred to these reviews for more comprehensive findings and for the sources of all the research material presented here.

1.1 PROGRESS AND BENEFITS OF DEINSTITUTIONALISATION

Deinstitutionalisation is the considered the single most significant policy development for people with disabilities since the post war period (Mansell & Ericsson, 1996). While definitions abound, deinstitutionalisation has been described as *'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 IASSIDD[3] Special Interest Research Group on Comparative Policy and Practice, 2010: p.104). The benefits experienced by people with intellectual disabilities when moving from institutions to the community are well established by a very substantial body of research, supporting the assessment of a leading international disability authority, Professor Jim Mansell, that the evidence has '*consistently shown that community-based services are better than institutions'* (2005, p. 23). Despite this research evidence, and the widespread adoption of international rights instruments and national policies, deinstitutionalisation is not enjoying speedy and smooth advances. Indeed, in pioneering countries in Scandinavia and the UK, a trend is currently developing for larger community group homes and community-based institutions. A recent report for the Academic Network of European Disability Experts (ANED)[4] examining implementation in 25 European countries found that few are even close to achieving strategic commitments (Townsley, Ward, Abbott, & Williams, 2010). Common challenges are local resources, regional differences in interpreting national policy, and lack of leadership.

1.2 PROGRESS AND RECENT POLICY ON DEINSTITUTIONALISATION IN IRELAND

Ireland's nationwide deinstitutionalisation programme lags behind many European countries, with congregated settings still providing services to nearly half of adults receiving residential supports (Health Service Executive, 2011). The *Deinstitutionalisation and Community Living Outcomes and Costs* report on changes across Europe (Mansell, Knapp, Beadle-Brown & Beecham, 2007) identified

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[1] Linehan, C., O'Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., McConkey, R., & Staines, A., (2014). Mapping the National Disability Policy Landscape. Dublin, Trinity College Dublin. Available to download at http://www.fedvol.ie/Moving_Ahead_Reports_available_to_Download_Now/Default.2078.html

[2] Tatlow-Golden, M., Linehan, C., O'Doherty, S., Craig, S., Kerr, M., Lynch, C., McConkey, R., & Staines, A. (2014). Living Arrangement Options for People with Intellectual Disability: A Scoping Review. Dublin: Trinity College Dublin. Available to download at http://www.fedvol.ie/Moving_Ahead_Reports_available_to_Download_Now/Default.2078.html

3 International Association for the Scientific Study of Intellectual and Developmental Disabilities IASSIDD website https://www.iassidd.org/

[4] ANED website http://www.disability-europe.net/

three stages of changing to supporting independent living: (1) *Transforming and reforming institutional care:* buildings and support services are supplied separately; (2) *Community living*: providing options and support in the community and (3) *Independent living*: support for people to live in their own homes and have choice and control through independent budgets. The 2010 ANED report (Townsley et al., 2010) placed Ireland midway between Steps 1 and 2, probably optimistically, as the separation of buildings and supports (Step 1) has yet to be realised for most people with intellectual disabilities. The most recent evaluation of services, the Value for Money and Policy Review of Disability Services (Department of Health, 2012), described progress as a "slow and tentative drift", with many agencies at different stages of the journey.

This poor progress in Ireland is not for want of policy in the area. Since the mid-1990s, 16 key national disability policy reports aiming to transform disability services have been published in Ireland, six of these alone since 2011. These are summarised in the *Moving Ahead* policy review (Linehan et al., 2014). Four of the most recent policies are briefly outlined here (Table 1); in combination they call for Ireland to move to a more person-centred system of supports for people with disabilities, with choice and control (including financial control) as central tenets of these reforms. This will require dismantling the current system of block funding large statutory and non-governmental providers, and creating more equitable and accountable services.

Table 1.1: Key disability policy in Ireland since 2011
2011   Time to Move on from Congregated Settings: A Strategy for Community Inclusion.
2011   National Housing Strategy for People with a Disability 2011-2016.
2012   New Directions: Review of HSE Day Services and Implementation Plan 2012-2016.
2012   Value for Money and Policy Review of Disability Services.

Time to Move On from Congregated Settings, A Strategy for Community Inclusion (Health Service Executive, 2011), defined congregated settings as those supporting ten or more people with an intellectual disability. It noted that over 4,000 people with disabilities still lived in 72 congregated settings in Ireland, and that between 1999 and 2008, admissions to congregated settings exceeded transfers out of them. Developing proposals for community-based, person-centred options, the report proposed that in the future, no setting in the community should support more than four people with disabilities; that no new congregated settings should be developed or new admissions sanctioned; and that the delivery of housing for those transitioning to the community should be completed within a seven year timeframe.

The *National Housing Strategy for People with a Disability 2011-2016* (Department of the Environment, Community and Local Government, 2011) addressed the mainstreaming of housing supports for persons with disability. The report noted that local government will face significant financial implications in implementing the recommendations of *Time to Move on from Congregated Settings*: an annual budget for implementation was estimated at €1.9 million, rising in annual increments of €1.9 million, resulting in an annual expenditure of €13.3 million from 2016. The report concludes that the proposed seven year timeframe for implementation is unlikely to be realised.

New Directions: Review of HSE Day Services and Implementation Plan 2012-2016 (Health Service Executive, 2012) examined day services, proposing a '*modern service that can respond to these unique and diverse individual needs'* (p. 13). Stakeholders, including people with disabilities, family members, carers and people working in the disability field, commented on the many activities available, but those working in intellectual disability services were critical of *over-nursing* of people

using services. Stakeholders called for day services that would support individuals to do *'ordinary things in ordinary places'*. People with disabilities stated however that there was insufficient one-to-one support and they felt *'controlled'* rather than facilitated.

Finally, the *Value for Money and Policy Review of Disability Services* (Department of Health, 2012), in a wide-ranging programme of reform to disability services, prioritises the development of community-based supports for individuals living in congregated settings. It defined these as domestic-style houses or apartments dispersed throughout the community supporting between one to four occupants, where neighbouring houses are occupied by members of the wider community.

The Value for Money Review evaluated existing statutory and non-statutory disability services in Ireland. It concluded that many were congregated and have segregated people with disabilities from local communities; and that despite considerable investment (i.e. a Multi-Annual Investment Programme totalling €900 million, 2006-2009) the current model of service had not met its objectives. Noting poor transparency in the rationales underlying existing standardised block funding of service providers, the Review proposed funding based on individual need instead. It proposed introducing competitive tendering for services, with Service Level Agreements (SLAs) between commissioners and disability service providers containing detailed performance indicators to specify outcomes.

The Review estimated the full disability budget for 2009 at €1.859 billion, €1.789 billion of which (net €1.5 bn) was funded by the HSE. Pay costs, estimated at 84%, were observed to have increased 35% from 2005 to 2009. As the workforce was highly professionalised (43% nursing or social care/ therapy professionals), a 10% shift to non-professionals was estimated to reduce costs by €3.5 million annually. The Review also highlighted a significant lack of information within the sector: unit cost data were undefined for many services; agreed outcomes were lacking, as were a set of national indicators. In reviewing disability services 'outputs', the Review noted that there was marked variation by region and by type of service provider (HSE or non-statutory), yet no evident reason for this. Such findings detail clearly that current disability support services are failing to meet policy goals, are financially unsustainable and are regionally inequitable. The Review noted that '*an extensive amount of detailed analysis will be required to develop a migration plan from the current way of delivering disability services to the point where service provision, administrative structures and governance procedures all support the achievement of the proposed vision and goals'* (p.176).

1.3 A history of poor implementation in Ireland

The stark findings of the Value for Money Review (Department of Health, 2012) unfortunately reflect a historical pattern of inadequacies in disability services in Ireland (see the *Moving Ahead* policy review; Linehan et al., 2014). There is a consistently poor track record of financial accountability and service monitoring among some disability organisations. In 2005, the Comptroller and Auditor General reported extensive administration, service and financial accountability deficiencies[5]. By 2012, the Value for Money Review concluded that such deficiencies challenged effective service monitoring (Department of Health, 2012). Specifically, performance (outcome) indicators have been identified as necessary by successive reviews since 1996, yet in 2012 there had still been *little progress … in*

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[5] *These were: the absence of service agreements and provider plans; late and non-receipt of audited accounts; acceptance of unaudited accounts; failure to reconcile grant with audited accounts; overpayment of grant; failure to maintain grant registers and grant files; no aid and appliance recipients register. The absence of: completed application forms; grant approvals; tax clearance certificates; Revenue Commissioners' confirmation of charitable status; registers recording receipt of audited accounts; certificates confirming satisfactory service by grantee; written procedures; review of monitoring procedures; formal evaluation of services; receipts for grant payment amounts; and review of organisations compliance with conditions attaching to funding (Comptroller & Auditor General, 2005, Appendix B)*

developing national outcome indicators (Department of Health, 2012, p. 132). Despite a particular concern about the lack of service monitoring or review, again, in 2012, the Value for Money Review reported the HSE had no information about outcomes, number, or even the existence of Service Level Agreement (SLA) reviews. While such shortcomings have been noted since 2005 by the Comptroller and Auditor General, who indeed queried whether the necessary competencies and infrastructure were available to implement the required change, the more recent findings of the Value for Money Review (Department of Health, 2012) suggest many of these systematic deficiencies remain.

Non-profit organisations play an unparalleled role in disability services in Ireland (Department of Health 1994, 1996; Department of Health and Children, 2001). However, rather than focusing on individuals' needs they may arguably be driven by organisational missions or individual personalities; as a result, they may decide aims with little consultation; resist change; and refuse to share information, transfer funding or facilitate moving people to different living arrangements (Power & Kenny, 2011; Ryan, 1999). These organisations would not be alone in their resistance to change; similar resistance has been observed internationally (Donoghue, 2002; Power & Kenny, 2011) where state and voluntary sector interdependence has led to pervasive blurring of boundaries and problems with accountability (Kramer, 1994).

To conclude, there is considerable evidence that successive attempts to introduce greater transparency and accountability in the disability sector in Ireland have been unsuccessful. Reviews have repeatedly found little progress on funding transparency, service agreements and outcome indicators among other issues. Large-scale change is required; yet without formal monitoring, the *'slow and tentative drift'* identified by the Value for Money and Policy Review will likely continue.

1.4 CHALLENGES OF DEINSTITUTIONALISATION FACED IN ALL JURISDICTIONS

Ireland is not alone in facing challenges to the process of deinstitutionalisation. There is ample evidence that institutional life can be re-created through attitudes and practices in smaller settings: *'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). More recently questions are being raised as to whether community services are offering the necessary supports or choice of living arrangements envisaged in the aspiration of community living (Tossebro, Bonfils, Teittinen, Tideman, Traustadottir, & Vesala, 2012).

Research findings identifying clear benefits of deinstitutionalisation are detailed in the research review conducted as part of *Moving Ahead* (Tatlow-Golden et al., 2014). Challenges exist in the interpretation of these findings as typically findings are pooled across a variety of community living options; as a consequence, it is difficult to assess which options provide the greatest benefits, or which, if any groups of people with intellectual disabilities may experience diminished outcomes in particular settings. A limited evidence-base exists which has explored outcomes in different community living options. These data indicate that dispersed housing generally fares better than campus or community-based clusters, albeit intentional communities have distinct benefits for a minority of individuals (Emerson et al., 2000; Mansell and Beadle-Brown, 2009). Community group homes, the most prevalent form of community living in Ireland and elsewhere, have been found to be less than optimal in cases where large numbers of people are supported, or where institutionalised practices are replicated.

The views of people with intellectual disabilities, clearly paramount, are rarely reported. Some individuals seek independent living, while others' stated preference is for non-community options. Many report a lack of choice about where and with whom they live; strained relationships among co-

residents have been reported. A noted trend in the evidence-base is the very high satisfaction levels reported for all living supports options, albeit this may reflect a reluctance to criticise services that provide support. Family members such as parents and siblings typically feel their needs are ignored and that social attitudes to disability are reflected in poor funding and implementation failures. Some families are reluctant to co-operate with moves to community living, often based on fears that supports will be insufficient.   Typically, family members hold very favourable views of clustered settings, although in time, many express a preference for more independent community options.

Individuals with higher support needs (e.g., those with behaviours that challenge, with profound and multiple disabilities and those who are ageing) often receive particularly poor supports, yet the quality of these supports is deemed the 'acid test' of policies advocating community living. People with behaviours that challenge are often placed in institutions or out-of-area; those with profound and multiple disabilities may experience physical and social isolation. Services struggle to provide 'ageing in place', the optimal support.

Community-based supports should promote relationships between people with disabilities and others in the community. Social inclusion and community participation lie at the heart of normalisation and social role valorisation, and are key rights under the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006). *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).

Social inclusion has yet to realise the aspirations implicit in community living for people with disabilities. People with intellectual disabilities are twice as likely as the general population to experience social isolation from family and friends. Social networks of people with intellectual disability are typically restricted to staff or other persons with disability met through shared services; rarely including people met through community activity. Management and staff attitudes and practices are central to social inclusion. Staff practices in particular may cause challenges where staff fail to change their role from one of caring to one of support. People with intellectual disabilities call for greater staff support in acquiring skills for using money and navigating the local area, and re-evaluation of risk perceptions that may inadvertently limit social inclusion. More globally, community characteristics linked to greater integration are unknown. Neighbours express concerns about lack of reciprocity, accountability and appropriate social distance from people with intellectual disabilities; and academics call for research to include views and experiences from the community, rather than focusing solely on experiences of those support by or working for disability organisations.

The move towards more individualised services may be enhanced by developments in areas such as advocacy and active skill training. Advocacy for people with intellectual disabilities remains under-developed in many jurisdictions. Greater professional awareness of its meaning is required for managers and practitioners to relinquish more power to people with intellectual disabilities, self-advocacy groups and professional advocates. Active support, which counteracts the frequent inactivity, boredom and isolation experienced by people with intellectual disabilities, is a key component of deinstitutionalisation. *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). Training in techniques such as active support is required if staff are to be equipped to move from providing 'care' to facilitating engagement in activities in which the person has an interest. Proponents argue this can only be achieved in a person-centred environment, and not in hospitals, intentional communities, or cluster housing.

1.5 KEY FACTORS TO BE CONSIDERED WHEN PLANNING FOR DEINSTITUTIONALISATION

Deinstitutionalisation plans must be costed, with ring-fenced funding, to account for major re-housing as well as supports in the community. Given this complexity, planning must take place at regional or national level. *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). A complex process of staff training, service provision and co-ordination is needed. Staff following individuals to the community will require support to ensure they do not bring institutionalised practices and attitudes to the community. Similarly, individuals who move will require supports to coordinate an array of new services from public, voluntary and private providers, each of which may entail differing funding streams, eligibility criteria and ethos.

Any closure of large institutions needs to consider the impact on the local economy. Staffing levels are likely to be lower in community services, and it is also unlikely that all former residents will find accommodation locally; they may move to where their families live or elsewhere. In some areas, an institution may be the main employer for generations of the same family. Although community services may provide employment for some, strategic planning is required to source additional opportunities. Local staff who cannot be redeployed may be offered redundancy or early retirement.

Closing large institutions and replacing them with inclusive, well-supported community services is a complex process driven by multiple, often incompatible demands. It requires planning, coordination and implementation by a variety of agents, and it requires resources. The Irish and international studies presented in the research review (Tatlow-Golden et al., 2014) provide valuable, if salutary, lessons. Many individuals have moved from large-scale settings to smaller ones that are similarly institutionalised. Social inclusion is poor; and crucial supports such as advocacy and active support are often absent, with staff unaware of these practices, untrained in them, or unaccepting of them. Therefore, many changes are required to achieve the goal of inclusive, actively supported community living for people with intellectual disabilities.

A particular challenge in Ireland is implementation. As noted above, there has been, for a number of decades, a consistent gap between what is proposed by reviews, reports, and policy in disability services, and what is actually implemented. Indeed a recent evaluation of implementation across Europe noted that in Ireland, *the rhetoric does not match the reality. There is a vision, but no clear direction, leadership or mandate to put this into practice at local level* (Townsley et al., 2010, p.16).

Consequently, this introduction turns to summarise research findings on barriers and facilitators of the process of achieving fundamental change in large-scale organisations. As this is a critical issue, yet the body of research in this field is sparse in relation to intellectual disability services, we present findings regarding organisations in some detail.

1.6 THE ROLE OF ORGANISATIONS IN DEINSTITUTIONALISATION

Achieving change in intellectual disability organisations is an ongoing process requiring perseverance, commitment and adaptation to local circumstances for a range of organisational agents including disability organisations, commissioners, and government agencies. Surprisingly, however, the role of organisations and agencies in deinstitutionalisation is rarely researched.

Contextual factors, such as policy, government officials, and funding allocations, each combine to influence the success of large-scale change in organisations and agencies. So to do within-organisational factors such as culture; attitudes to change; management clarity, coherence, strategy

and support; leadership ability to change existing mental models; rewards for staff input; and staff skill. Change is needed at every level, so that aims from policy level are practiced at the level of staff day-to-day implementation. In addition, an overall implementation and management plan is needed to achieve deinstitutionalisation, as implementation frameworks influence outcomes.

A policy "push" for change, as currently exists in Ireland, can increase success, particularly if funding is provided. However, research indicates that if organisations or agencies are strongly identified with former values, or are unable to detach from former structures or ways of working, they may not be able to change and will ultimately close. To achieve radical new ways of working, organisations need to reframe their internal culture, operations, and practices. They also need 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 which may be implemented in their transition to new models of service delivery.

In a seminal review of change in complex health service systems, Greenhalgh, Robert, Macfarlane, Bate, and Kyriakidou (2004) concluded that the success of change in large-scale human services such as the National Health Service in the UK is affected by practical factors (e.g., clear documentation or training), as well as less visible ones, such as perceptions of those responsible for implementation. On a practical level, change is more likely to succeed if introduced incrementally, with training and supports; if it has clearly articulated, transferable knowledge that is customised to the context; and if it is modified to suit the needs of those adopting it. Less visible factors influencing change include if staff perceive the current way of working as unsustainable and the new approach as having clear benefits; if the new approach is perceived as simple to use (or if demonstrations reduce perceptions of complexity); if changes are deemed compatible with organisational and professional values, norms, perceived needs and ways of working; and if changes are considered effective or cost-effective.

1.7 ORGANISATIONAL STRUCTURE, CULTURE, LEADERS AND STAFF: THEIR ROLE IN ORGANISATIONAL CHANGE

Organisations are often portrayed as top-down hierarchies, in which policy directs leadership and management, who in turn determine activities on the ground. In reality, the everyday, on-the-ground, small-scale interactions often determine an organisation's effectiveness and outcomes. 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. *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.

Less visible features, such as culture and emotions, exert a powerful influence in organisations. Culture is the explicit and implicit assumptions, attitudes and practices of managers and staff – formal policies and processes and taken-for-granted customs and practices including stories, rituals and routines – that influence people's roles, positions, behaviours and interactions. Individuals are socialised into this, developing mind-sets and ways of behaving that lead them to prioritise prevailing practices and resist new ones. Emotions affect information processing, influencing sense-making in times of uncertainty and staff interpretation of change. 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.

There is strong evidence that clear strategic leadership supports change in human service organisations. Leaders are central to innovation, managing strategic goals and contributing to the

organisation's overall environment. However, they may also create barriers to change, if they fail to participate in all aspects of a change programme; engage in poor communication with staff; set unrealistic expectations; practice remote or autocratic management, ignoring employee ideas; or lack credibility, skills, or experience in employees' eyes.

Staff are also key to organisational change. When implementing new ways of working, staff do not passively adopt changes. Interacting purposefully and creatively with changes, 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). They are not innately resistant to change, but may fear loss of status, pay or working conditions – realistically so in the case of deinstitutionalisation, as they may need to be more flexible, working alone more often, and on less clear shift patterns. This has implications for job-related satisfaction, stress, and turnover, issues that can affect the success of organisational change.

Beliefs, values and mental models are particularly difficult to change, and organisational change often fails because *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). Frequently, even where current services are not workable, people may block reform that threatens deep-seated institutional features, ways of life, or beliefs. For example, deinstitutionalisation entails a fundamental shift from a philosophy of 'care' to one of 'support', which may be particularly challenging. Leaders can overcome resistance to change in intellectual disability organisations by 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. Change should also be paced to allow for questions, absorption, and variations in staff receptivity.

1.8 CREATING ACCOUNTABILITY IN INTELLECTUAL DISABILITY SERVICES AND ORGANISATIONS

There is international agreement that transparency and evaluation are critical for high quality intellectual disability services. The urgent need for accountability in disability services in Ireland is undisputed. Most recently, the Value for Money and Policy Review of Disability Services repeated the call for the implementation of SLAs between service commissioners and providers with clear, detailed and specific performance indicators, ongoing service monitoring and compliance reviews.

Such an approach to accountability in services reflects the 'new public management' (NPM) service model. This aims to achieve quality services and cost control through market approaches, seeking efficiency, financial management and consumer choice. Efficiency is defined as the cheapest means of achieving goals. Expectations of service commissioners are specified precisely, with assessment metrics and roles and outcomes specified in advance. NPM employs 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.

NPM systems generate an extensive auditing and quality control regime. Vigorous critiques suggest it provides illusory choice and loss of accountability, encouraging services to engage in poorly co-ordinated, target-chasing approaches. Importantly, although it is assumed 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 UK's 2002 *Valuing People* white paper.

In contrast, 'experimentalist' governance, which also seeks accountability, suggests a more flexible approach may deliver more effective outcomes. It is considered ideal for systems with broad service goals, such as 'child protection' or 'a good education', and has been effective in systems with deep-rooted resistance to change. It may therefore be well suited to intellectual disability services, where quality of life goals are broad and need to be adapted to abilities and circumstances of each individual. Experimentalist governance has been applied successfully to child welfare, public education and community policing reform in the US and to the Finnish education system. Experimentalist governance takes the position that effective services must adapt to individual or local needs, and that inherently complex and ambiguous frontline issues need interdisciplinary assessment and solutions, and flexible responses. Commissioner/ agency relationships are constructed from a learning orientation, rather than a hierarchical one. Replacing the all-too common combination of *rules and furtive discretion*, iterative diagnostic monitoring creates *dynamic accountability* (Sabel & Zeitlin, 2012). Rather than checking compliance with pre-set norms, detailed file reviews and interviews with all stakeholders (child, family, other caregivers, professionals, etc.), mean that goals are adjusted as the situation requires, and systemic problems are identified.

Evaluations of deinstitutionalisation in England and Ireland suggest that flexibility is important, echoing the experimentalist governance approach. Mansell and colleagues (2007) cite the UK example of Darenth Park, where original institutional closure plans (which had an option for smaller congregated settings) were halted when the success of dispersed housing in the community was reviewed. Evaluation of demonstrations in Ireland by McConkey, Bunting, Ferry, Garcia-Iriarte and Stevens (2013) found that, despite policy directives proposing moves to more personalised options, few people with intellectual disabilities moved to any options other than community group homes. Flexible planning would permit a swift and targeted response to this pattern.

1.9 REGIONAL AND LOCAL DIFFERENCES IN PROGRESS TO DEINSTITUTIONALISATION

Inter-country variations in progress to deinstitutionalisation have been identified. A similarly pressing but much less well-understood issue is the existence of widespread *within*-country regional variation in the process of deinstitutionalisation. This pattern has been reported, for example, in the US, UK and Finland. Recently, marked within-country variation in deinstitutionalisation has also been documented in detail for Ireland. McConkey, Kelly, Craig, and Mannan (2013) used Ireland's National Intellectual Disability Database (NIDD)[6] data to explore progression to community-based services for adults (20 years and over) with intellectual disability. One of the few international examples of such a dataset, the NIDD is a national service planning tool and is updated annually. It records demographic details and current service provision (including residential setting) of individuals who receive or require disability specific services.

When initially established in the 1990s the NIDD organised information according to the then-existing eight administrative Health Board regions in Ireland. This allowed analyses to explore not only national trends but also regional ones. Health administration has changed several times in the intervening period, and current NIDD annual reports refer to four HSE regions. However, to track

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[6] *The National Intellectual Disability Database is managed by the Health Research Board on behalf of the Department of Health. It aims to provide a comprehensive and accurate information base for decision making in relation to the planning of services for people with intellectual disabilities. More information can be found at http://www.hrb.ie/health-information-evidence/disability/*

individuals and provide comparisons with earlier data, studies often still refer to the previous eight former Health Board regions; that convention was followed by McConkey and colleagues in their exploration of intra-country variation in Irish disability services and will also be followed in this report.

For ease of analysis, McConkey et al (2013) divided accommodation into two broad categories: 'congregated' settings which included institutions, campus clustered housing, psychiatric hospitals, nursing homes, and specialised settings for those with challenging behaviours or complex physical health needs. 'Community' settings were, for the most part, group homes of about six individuals with staff support. A note on terminology is warranted regarding the application of 'congregated' and 'community' living options in this study. For McConkey et al (2013), a clear distinction is drawn between community and non-community living, with the latter termed 'congregated'. This terminology differs from other usage where the term 'congregated' refers to large number of individuals with disabilities living together, whether in the community (i.e. in large properties or clusters of community housing) or in segregated settings (i.e. such as hospital, campus or institutional settings) (Health Service Executive, 2011).

The NIDD shows substantial progress in deinstitutionalisation from 1999-2009; the national ratio of adults with intellectual disabilities living in congregated compared to community settings was 2:1 in 1999 and had fallen to nearly 1:1 by 2009 (with 4,120 adults living in congregated settings and 3,838 living in the community). In that time, there was a 45% increase nationally in adults aged 20 years and over living in community settings, and an 11% decrease in congregated settings.

These national findings, however, conceal substantial regional differences. Although all the Republic's eight former Health Board regions saw increases in the proportions of adults supported in the community from 1999 to 2009, the increases varied substantially. In the Western region there was a rise of just 24% compared to a rise of 80% in the Midland region. Indeed, in three of the eight regions small increases (of 2-6%) were observed in the proportions of adults supported in *congregated* settings (North-Eastern, Mid-Western and Southern). These differences are summarised in Table 1.2.

Table 1.2: Rounded percentages and numbers (n) of adults in Ireland's eight health service areas living in congregated and community settings in 1999 and 2009, and the percentage differences*

HSE Region	Congregated			Community		
	1999 **% (n)**	**2009** **% (n)**	*1999-2009* *Difference*	**1999** **% (n)**	**2009** **% (n)**	*1999-2009* *Difference*
Eastern	67% (1664)	58% (1555)	*- 6.6%*	31% (742)	42% (1118)	*+51%*
Midland	71% (310)	47% (202)	*-35%*	29% (126)	53% (227)	*+80%*
Mid-Western	59% (383)	51% (395)	*+3%*	42% (272)	49% (385)	*+38%*
North-Eastern	70% (328)	59% (348)	*+6%*	30% (142)	41% (246)	*+73%*
North-Western	66% (362)	50% (278)	*-23%*	34% (188)	50% (275)	*+46%*
South-Eastern	60% (505)	43% (399)	*-21%*	40% (339)	57% (538)	*+59%*
Southern	62% (636)	56% (648)	*+2%*	38% (393)	44% (503)	*+28%*
Western	49% (425)	35% (295)	*-31%*	51% (441)	65% (546)	*+24%*
National	**64% (4613)**	**52% (4120)**	*-11%*	**36% (2643)**	**48% (3838)**	*+45%*

*Adapted from McConkey et al (2013)

Identifying longitudinal differences in proportions of people supported in congregated and community settings is instructive, but it is possible that changes in such proportions may reflect factors other than

moves from institutions to the community (e.g. increased birth rates in the general population in earlier cohorts, reflecting a greater need for supports as they reach adulthood). Therefore, to examine regional patterns of moves to the community specifically, McConkey and colleagues (2013) identified the sub-group of NIDD-registered adults who were living in congregated settings in 1999 who were still registered on the NIDD in 2009 (n = 3579). Identifying these individuals' 2009 residential settings, the researchers were able to highlight the health board regions where few moves to community living were being achieved. For example, the proportion of individuals who moved from congregated to community settings between 1999 and 2009 was just 8% in the Southern region and 11% in the Eastern region, compared to 34% in the South-Eastern region.

As noted above, the factors underlying regional differences in proportions of community and institutional supports are not well understood. Historical regional differences are likely to play a role, perhaps particularly so in Ireland, where services were once provided almost exclusively by religious orders which based themselves in locations suited to them and which were largely autonomous. A "more intriguing" question, however, addresses the issue of why *current transitions* from congregated to community living differ between regions, as McConkey et al. (2013) have identified.

Organisational factors such as service provider policy and practices, leadership and staff may play a role. The ANED deinstitutionalisation study across Europe noted that a cultural shift spurred progress in many organisations that embraced change, with reconfiguration promoted by policies, dedicated teams and leadership. Exploring local organisational factors may be particularly relevant in Ireland, where most resources and power are held by service providers, and is of interest as the role of barriers and facilitators of change at local agency level is little explored to date. Furthermore, the possible role of broader region-level factors is also unexplored in the research.

Currently, in Ireland, there exists a context of policy calls for rapid deinstitutionalisation, a long history of poor implementation and little accountability in disability services in both statutory and non-profit sectors, as well as new evidence for strong regional differences in the implementation of community living for people with intellectual disabilities. *Moving Ahead* was designed to address some of the questions. Targeting two regions in Ireland with strong disparities in deinstitutionalisation, *Moving Ahead* aimed to identify factors contributing to contrasting regional trends to progress to community living.

To achieve this goal, two broad research questions were formulated, each with five specific sub-questions:

1. What are the barriers and facilitators of deinstitutionalisation in Ireland, in two regions which differ in progress to community-based living for people with intellectual disabilities?

    i. What are the views of major stakeholders of different living supports for people with intellectual disability?
    ii. What do stakeholders cite as barriers and facilitators of community-based living?
    iii. What role do organisational culture and ethos play in developing community-based living?
    iv. What factors distinguish residential provision in the two regions?
    v. What role do local and regional issues play in developing community-based living?

2. For people with intellectual disabilities in the two regions, how do their characteristics and quality outcomes differ if they live in dispersed community-based settings compared to congregated settings?

i.   How do their demographics and support needs differ?
ii.   How do their health status and access to health services differ?
iii.   How do their quality outcomes differ (e.g. exercising choice, community engagement, quality of life)?
iv.   How do the physical staffing practices and staffing levels differ and can indicative costs be determined using staffing levels?

2. Methodology

In order to identify factors affecting the development of community-based supports, this study explored stakeholders' experiences and views of residential provision for people with intellectual disabilities in two regions in Ireland, each with a different level of progression towards community living.

The study also aimed to identify the characteristics and quality of life experienced by people with intellectual disabilities in congregated versus dispersed community settings in these regions. The term 'dispersed' community living is used to reflect the Health Service Executive's (2011) recommendation in *Time to Move on from Congregated Settings*, that individuals with disabilities should live in houses that are scattered throughout the community. The rationale for this recommendation was to avoid any congregation of people with disabilities within communities, notably cluster settings where individuals with intellectual disability are supported in a number of properties in close proximity (Mansell & Beadle-Brown, 2009).

Three key objectives guided the design of this study:

- To engage all main stakeholders in this complex human services system, including people with intellectual disabilities, families, and those working with the disability field;

- To build a picture of services across regions and across different service types, in terms of service provision, decision-making, and the experiences of those working in, and those availing of, services;

- To triangulate information across regions, service types and informants, exploring similarities and differences in stakeholders' perspectives, and identifying any regional, local and organisational factors.

To meet these objectives, it was necessary to be sensitive to real-life, contextual issues, and to derive knowledge from multiple sources. The research design was chosen to reflect these requirements. To explore the 'how' and 'why' of a contemporary phenomenon in its real-life context, a multiple case study design is recommended (Yin, 2003). Informed by the philosophical approach of pragmatism, the study drew on mixed methods to source information from multiple perspectives (Cresswell, 2009).

The chosen study design was a mixed methods, multiple case study, with embedded units of analysis:

Mixed methods: The study was a concurrent mixed methods design, incorporating both qualitative and quantitative approaches at each stage of the project: the research question, design, data collection, analyses and conclusions (Tashakkori & Cresswell, 2007).

Multiple case study: The case study units were the eight former health board regions in Ireland. Of these eight, two contrasting regions were identified to participate in the research, each of which had differing rates of closure of congregated settings and development of community services.

Embedded units: Within each region, agencies providing residential services to people with intellectual disabilities, and key stakeholder groups such as people with intellectual disabilities, family members, and staff in various roles, represented embedded units for data collection and analysis.

The study aimed to gather data from four sources:

- agency archival records;

- a survey of people with intellectual disabilities (completed by supported people themselves or by keyworker proxy, depending on levels of ability);

- focus groups and interviews with agency stakeholders;

- interviews with regional and national disability personnel and others working in allied fields.

Archival records

This portion of the study aimed to examine the last ten years of policy and practice documents (e.g. Annual Reports) from disability service providers participating in *Moving Ahead*. The aim was to extract information that reflected the changes over time in the ethos and practice of agencies.

Survey of people with intellectual disabilities (supported by keyworkers as necessary)

A survey was developed to explore key demographic information from a sample of people supported by participating agencies, as well as information on support needs; type of residential supports; health, well-being, quality of life and social inclusion, among other factors.

Interviews and focus groups with key agency stakeholders

Five groups of key stakeholders were selected through the participating agencies. These were:

- People with intellectual disability supported by the agency

- Families of people supported by the agency

- Direct support staff (including nursing and social care assistants who worked or had worked either in congregated or community settings)

- Clinicians

- Senior management

Interviews with regional and national stakeholders and experts

Interviews were conducted with selected stakeholders at both regional and national level.

- *Regional HSE service commissioners* to whom participating agencies reported.

- *Experts* working in mainstream services such as health, supported employment and housing were identified; the goal was to explore views on local priorities in service provision, accessibility and the capacity of the local community to support people with intellectual disability.

- *Experts in disability services* (connected to policy, advocacy and regulation) were invited to provide an over-arching national perspective beyond the confines of each case study, and to contextualise the findings from the other stakeholder groups.

Rationale for selection of regions, agencies and stakeholders

Three considerations guided the selection of regions, agencies and stakeholders participating in *Moving Ahead*.

- First, to identify stakeholder perspectives and underlying reasons for different rates of progress to deinstitutionalisation in Ireland, two regions were sought that contrasted strongly in their rates of progress to deinstitutionalisation.

- Second, the study aimed to examine views and experiences in different types of agencies providing residential services within these regions. The rationale for agency selection was therefore to reflect the variety of service provision in Ireland and to match agency types across the two regions.

- Third, views and experiences of all key stakeholders in these agencies were sought. Therefore, people with intellectual disabilities, their families, direct care staff, clinicians, and senior managers would be invited.

The following sections describe the process of selecting these case studies and each embedded unit of analysis. Table 2.1 below presents a summary of the research design.

Table 2.1: Summary of Research Design

Two regional case studies		Two contrasting regions with different rates of progress to deinstitutionalisation in Ireland	Mixed methods: Predominantly qualitative including a quantitative survey of persons supported
Embedded units of analysis:	Agencies	Within both regions: Three types of agency to represent service provision: Large, Small, and HSE	
	Within-agency stakeholders	Within each agency: people with intellectual disabilities, their families, direct care staff, clinicians, and senior managers	
HSE Commissioners and National Experts			

Selection of regions

As discussed in Section 1.9, an investigation of NIDD data from 1999 to 2009 (McConkey et al 2013) had identified marked regional variation in Ireland in community living options across the eight former health board regions in the country (the existing administrative units in 1999). In consultation with the *Moving Ahead* Steering Group, and with liaison with personnel from the NIDD who provided current data on the regions, two of these eight former health board regions were selected to be case studies in *Moving Ahead*. The criteria for selection were that the two areas would:

- Contrast sharply in development and delivery of community-based services

- Include a wide range of organisations providing disability services including statutory, faith-based, parent and family associations etc.

- Represent a wide range of living arrangement options including institutional, congregated, and community-based

Two former health board regions were identified using these criteria, with the most prominent criterion being that they contrasted sharply in their development of community-based services as measured by McConkey et al (2013). To avoid identifying the regions and participating agencies, the regions selected will be referred to in this report as:

- Region 1 (less progress to community living)

- Region 2 (more progress to community living).

Selection of agencies

Having selected two contrasting regions, disability organisations within the regions were selected. The types of participating organisations are summarised in Table 2.2. Again, selection was completed in consultation with the *Moving Ahead* Steering Group. The steps involved were:

For both regions, current NIDD data on agencies and people using residential services were consulted, as were raw data from the *Time to Move On from Congregated Settings Report* (supplied with kind permission of the Health Service Executive). Sampling frames were created and reviewed.

The goal for selection of participating disability organisations was to source the following matched organisations within each of the two regions:

- A statutory (HSE) service providing a range of residential options from institutional through to community-based options.

- A large non-statutory service agency providing a range of residential options from campus settings through to community-based options.

- A small non-statutory service agency which only ever provided community-based options. These smaller agencies were required to support enough people to allow the research team to source participants for focus groups of supported people, family and staff, as well as source participants for the survey of people supported by the agency.

- A mix of religious-founded and 'parent and family' services.

Six services were identified using these criteria; one HSE service, one of the larger agencies and one small community-based agency in each of the two regions. All services approached agreed to participate. Finally, to supplement survey data, one additional agency in each region was recruited. Thus, in total eight disability providers, four in each of the two regions, participated in *Moving Ahead.* These eight agencies accounted for 60.45% of all services provided in these two regions.

Table 2.2: Summary of types of regional agencies participating in *Moving Ahead*

	Region 1	Region 2
Statutory HSE organisation	This service provides institutional and on-site campus housing in addition to a range of community-based housing, some of which is dispersed, some in close proximity.	This service provides institutional and on-site campus housing in addition to a range of community-based housing, some of which is dispersed, some in close proximity.
Large non-statutory organisation	This service provides congregated on-site campus and community-based campus housing and a range of community-based housing, some of which is dispersed, some in close proximity. This agency was originally established by parents and friends in the 1950s.	This service provides congregated on-site campus and community-based housing, some of which is dispersed, some in close proximity. This agency was originally established by a religious body.
Small	This service has only ever provided a range of community-based housing, some of which is dispersed, some in close proximity. A small non-governmental agency, established by a local Parent and Friend organisation.	This service has only ever provided a range of community residential supports, some of which is dispersed, some in close proximity. A small non-governmental agency, established by a local Parent and Friend organisation.
Added	This is a large non-governmental agency, originally established by a religious body. The service provides congregated campus residential supports and a range of community-based supports, some of which is dispersed, some in close proximity.	This is a relatively newly established small non-governmental agency. The service provides dispersed community housing only.

2.4 ETHICAL ISSUES

Moving Ahead was reviewed and approved by the Research Ethics Committee at the Trinity College Dublin School of Social Work and Social Policy. In total, 12 agencies participated in the study; four in the pilot phase and eight in the study proper. Five of these agencies requested that the project be reviewed by their internal research ethics committees. The remaining agencies were satisfied with the ethical approval awarded from Trinity College Dublin and were requested to sign a letter of consent from the CEO confirming that ethical approval from Trinity College Dublin sufficed for their participation in the study. Ethical guidelines from the Trinity College Dublin School of Social Work and Social Policy; the National Disability Authority; and the Psychological Society of Ireland, were adhered to and both researchers involved in data collected were Garda (police) vetted.

The researchers have extensive national and international experience in conducting research with people with intellectual disabilities, and aimed to implement best practice in supporting them to participate. The team's practice was also informed by guidance from those project partners who were

experts by lived experience (with an intellectual disability or family members of an individual with an intellectual disability).

Communicating the nature of research effectively (its rationale, research questions, activities, risks, voluntary nature) is particularly important when researching with people with intellectual disabilities. The research team used best practice guidelines to produce accessible materials to fully inform people with intellectual disabilities before they agreed to participate. These were piloted with people with intellectual disabilities in several agencies, to maximise the possibility of obtaining informed consent from individuals with intellectual disabilities. However, a requirement for informed consent can, inadvertently, create a barrier to participation for those with more severe levels of disability.

To represent varying degrees of intellectual disabilities in the survey for the study, recruitment procedures applied in the intellectual disability field (previously employed by an Irish and UK Department of Health commissioned study[7]) were adopted. The procedure is as follows: informed consent is prioritised mindful that some individuals may be deemed unable to consent. Where necessary, a Clinical Director or equivalent was asked to provide guidance on capacity to consent. Individuals who provide consent are enrolled into the survey. Where an individual is deemed unable to provide consent, a family member/legal guardian is approached and invited to sign a Letter of Agreement regarding participation. In cases of no known family, the Clinical Director or Chief Executive Officer of the service is invited to sign the Letter of Agreement. The survey is completed by proxy on behalf of individuals enrolled to the study with the agreement of family/legal guardian/senior representative of the supporting agency. In this way those with higher support needs are facilitated to participate in the survey to ensure their representation in the sample. This process has been applied in the absence of legal capacity legislation currently being developed in Ireland.

2.5 SAMPLING AND PARTICIPANTS

Participating agencies were the sampling units in this study. They were provided with information on the study and potential participants (people with intellectual disabilities, family members, direct support staff, clinicians and senior management) were invited to self-select for participation through agencies. However, agencies were also asked to support recruitment so that, where possible, the focus groups, in particular, were reasonably representative in terms of gender and age. Agencies were provided with criteria from which individuals were invited to participate in the focus groups. These criteria were used to ensure that the groups reflected experience of the range of residential supports provided by the agency. As survey participation was anonymised it may be that some survey participants with intellectual disabilities also took part in a focus group.

People with Intellectual Disabilities

Survey*:* Seven agencies participated in sampling for the survey of people with intellectual disabilities. In a format prepared by the research team, all participating agencies were asked to supply an anonymised list (sampling frame) of individuals over 18 years of age to whom they supplied full time residential supports, to identify level of ability and residential setting type. In three large agencies, stratified random sampling, by level of ability and type of residence, was employed. In the four smaller

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[7] Walsh, P.N., Linehan, C., Hillery, J., Durkan, J., Emerson, E., Robertson, J., Hatton, C., Gregory, N., Kessissoglou, S., Hallam, A., Knapp, M., Järbrink, K., & Netten, A. (2000). *The Quality and Outcomes of Residential Supports provided for Irish Adults with Intellectual Disabilities. A Comparison of Quality in Irish Village Campus Settings and Group Home Settings.* Centre for the Study of Developmental Disabilities, National University of Ireland, Dublin.

agencies all those receiving residential supports were asked to participate. In total, 136 individuals with intellectual disability participated in the survey.

Focus Groups: Agencies were provided with accessible information on the proposed focus groups. Supported people were invited to participate. Inclusion criteria were being 18 years or older and receiving full time residential supports from the agency. In total, five focus groups were conducted with 42 people supported (three in Region 1, two in Region 2); most (64%) participants were women.

Family members

Information on the focus group was provided to all participating agencies. Inclusion criteria were being 18 years or older; being a parent, sibling or extended family member of a person receiving full time residential supports from the agency; be actively involved in the life of the person supported; represent a mix of the available residential supports provided by the agency; and be willing to contribute to the focus group discussion. Six focus groups were hosted, three in each region. In total, 40 family members participated, 20 in each region. 32 (80%) of the participants were women.

Direct support staff

Direct support staff in seven participating agencies were invited to self-select by their agency to participate in the focus groups. Agencies were asked to assist in disseminating news of the focus groups to staff aged 18 years or over who; provided residential support to adults with intellectual disability; had a minimum of two years' experience; represented the full range of residential supports provided in the agency; and who would be willing to contribute to the focus group discussions. In total, ten direct care staff focus groups were conducted at seven agencies with 87 direct support staff members participating, 37 in Region 1 and 50 in Region 2. The majority of participants (n=66; 76%) were women.

Clinicians

After consultation with agencies, it was evident that only the three larger agencies had capacity to host a focus group with clinical staff. Clinicians were selected via purposive sampling in consultation with senior management, aiming to ensure good representation of disciplines. Arrangements were made to host three clinician focus groups, but regrettably only one proved feasible, held in a large organisation in Region 1. Seven individuals attended, of whom six (86%) were women.

Senior agency personnel

A total of 19 senior management and senior clinical personnel were individually interviewed. These personnel included chief executive officers, general managers, policy development managers, disability specialists, area managers, sector manager and directors of nursing. All personnel were linked with the eight participating agencies in Moving Ahead. Ten of the interviewees were based in Region 1, nine in Region 2; most were men (n=11; 58%).

Regional HSE service commissioners

Agencies participating in *Moving Ahead* were asked to identify service commissioners in the HSE who had responsibility for their region. Six of seven commissioners who were invited to participate were interviewed.

Regional and national experts

Purposive sampling was employed to select individuals who could provide a national perspective on the current and future development of disability services in Ireland. Some of these individuals were

employed in the disability arena, such as advocacy, standards and policy, while others were employed in mainstream services such as education and health that are likely to play an increasing role in supporting individuals with disabilities as they move to local communities. These individuals were identified initially in consultation with the Project Steering Group and thereafter through a snowballing process from interviewees and participants in *Moving Ahead*. In total 17 experts participated in interviews, nine women (53%) and eight men (47%). Just one individual who was invited to participate in these interviews declined to do so, a 94% response rate.

Table 2.3: Number of individuals from each stakeholder group who participated in different data collection activities in Moving Ahead			
	Focus Group	**Interview**	**Survey**
People with intellectual disability	42	-	136
Family	40	-	-
Direct support staff	87	-	-
Clinicians	7	-	-
Senior management	-	19	-
Regional HSE Commissioners	-	6	-
Regional & National Experts	-	17	-
Total	**176**	**42**	**136**

Total participation rate

In total, 136 individuals participated in the survey, 176 individuals participated in 22 focus groups, and 42 individuals participated in individual interviews. In total, approximately 354 individuals participated in *Moving Ahead*. A definitive figure cannot be determined as there may be some double counting where individuals with intellectual disability who participated in the survey may also have participated in focus groups. The anonymised nature of the survey does not permit identification of possible double counting.

2.6 QUANTITATIVE AND QUALITATIVE METHODS AND MEASURES

As noted above, several different types of data were sourced for this study. This section describes the development of the survey of people with intellectual disabilities and the focus group/interview guides for all key stakeholders

Supported people and where they live: The development of the survey

To explore supported people's individual characteristics and the nature of the settings in which they live, a quantitative survey was developed. This aimed to identify basic demographics; individuals' support needs, health status, social inclusion, and life satisfaction; and the nature and characteristics of the settings in which they were supported. Databases, relevant literature and previous studies were examined and project partners consulted on question development. To ensure that relevant life domains were addressed, a number of sources were consulted. These sources included: (a) the

National Intellectual Disability Database (NIDD); (b) seven reviews of deinstitutionalisation literature, that were reviewed and summarised for this study (see research review; Tatlow-Golden et al, 2014); (c) a health indicator set developed by the Pomona Project (Perry et al, 2010) (d) a review of supported accommodation models commissioned by the National Disability Authority (NDA) (Walsh et al, 2007); and (e) an evaluation of individualised support commissioned by GENIO (McConkey et al, 2013).

Two brief surveys were developed[8]. One related to service and setting characteristics, and was completed by keyworkers. The other explored individual characteristics and views of the supported person. As far as possible this was completed by supported persons themselves with keyworker support; alternatively keyworkers completed the survey by proxy.

Supported Person: The survey assessed level of supports required with the Support Needs Scale devised for the Survey of Adults with Learning Disability in England (ALDE; Emerson, Malam, Davies & Spencer, 2005). Questions assessed the health status, medication use and heath service utilisation of supported people, and also behaviours that challenge. The survey also asked whether supported persons have an advocate independent from their service provider.

To assess social inclusion, questions asked about relatives and close friends; level of contact with each; and individuals' views of whether they have enough friends and how lonely they feel. For community inclusion, questions explored how often and with whom supported persons engaged in activities in the community such as going shopping, to the pub, for a meal, to the library or to the hairdresser, among others. Questions also asked about training or work. Finally, a set of questions explored personal life satisfaction and/or quality of life, drawn from Bergström et al's (2013) scale for satisfaction with life among people with mild to moderate intellectual disabilities living in community residences. This section of the survey could not be completed by proxy, as studies have shown that proxy responses on quality of life may differ from the perspectives of individuals with intellectual disabilities themselves (Janssen, Schuengel & Stolck, 2005).

Current Setting: This portion of the survey asked keyworkers to identify the nature of the setting in which the supported person lived, specifying accommodation type and whether it was one of a cluster. Further questions explored respite provision; setting ownership; whether housing and support were provided by the same organisation; and staffing levels in each setting. A further set of questions explored support practices with the goal of discriminating between community and congregated settings. Finally, project partners recommended additional items about individualised person centred plans; whether supported people had a say about who attends their planning meetings; whether they and neighbours knew each other by name; and whether the neighbourhood was considered safe.

Semi-structured focus group and interview schedules

Focus groups were chosen for most stakeholder groups at agency level: individuals with intellectual disability, family members, direct care staff and clinicians. Individual semi-structured interviews were chosen as a method for senior agency personnel, HSE commissioners and national experts due to practical reasons such as confidentiality and challenges of organising a focus group with people based in different locations.

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[8] For a full set of sources of all questions included in the survey please email Dr Christine Linehan (christine.linehan@ucd.ie)

For focus groups and interviews, topic guides were developed with reference to the literature and the research questions. For people supported, family members, and direct care staff or clinicians, these were designed to elicit conversation about different models of residential support commonly found in Ireland, and movement from congregated to community-based settings. The topic guides for family members and direct care staff also explored disability policy, support in the community, closure of congregated settings and regional issues. Direct care staff and clinicians were also asked about the culture in the organisation. Four interview schedules were developed to accommodate distinctions in roles and experiences between senior agency management, HSE commissioners, and regional and national experts. All asked about the disability services landscape (including national disability policy and the perceived impact of the economic recession) and development of community-based services, as well as barriers and facilitators to community-based services and relocation of people from community to congregated settings. Agency managers, regional and national experts were also asked about the closure of congregated settings. Senior agency management were also asked about current admission policies and practices, and HSE commissioners and national experts were also asked about housing policy.

Pilot study of survey of supported people and focus group topic guide

Direct support staff and 35 supported people in four agencies facilitated the piloting of the survey, information sheets and consent forms. Respondents were asked to rate the accessibility (ease of understanding, appropriateness of illustrations) of the Easy-to-Read information sheet and consent form for people with intellectual disabilities. Direct support staff were asked to indicate ease of discussing the project with supported people and helpfulness of the information sheet. Feedback was largely positive but forms indicated that staffing levels were difficult to assess. This portion of the form was amended with the support of senior management in one disability agency to address these difficulties. A focus group topic guide for staff and clinicians was also piloted with one service agency. Feedback allowed the topic guide to be refined and informed the development of the topic guides for the other stakeholder groups.

2.7 PROCEDURE

Survey

Seven of the eight participating agencies participated in survey completion. In each agency, a liaison staff member assisting in survey recruitment was provided with information sheets and consent forms separately for persons supported, family members and direct support staff; and with copies of the surveys. The research team made one or more survey site visits and were available throughout data collection to address any queries. A first inspection of returned surveys identified that keyworkers were again challenged to provide certain types of information, particularly about the characteristics and staffing levels of the settings in which people were supported. The research team therefore reverted to agencies to source information where possible.

Focus groups and interviews

Over six months, two members of the research team conducted 22 focus groups and 42 interviews with four main stakeholder groups within each agency: people with intellectual disabilities, family

members, direct care staff, clinicians, and senior management, as well as with regional and national experts.

Two researchers rotated focus group facilitation and co-facilitation. Participants were presented with a descriptor and visual image of four of the most commonly availed of residential supports for adults with intellectual disability in Ireland and were invited to discuss each in turn. For people with intellectual disabilities, verbal descriptions were simplified and further picture prompts (e.g. photos of a community group home, campus settings) were used. During staff and clinician focus groups, a definition of organisational culture was used as a visual prompt: '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' (Drennan, 1992, as cited in Gillett & Stenfert-Kroese, 2003).

Semi-structured interviews were conducted with senior agency personnel, HSE managers and national experts, rotated among two members of the research team. Focus groups ranged in length from 58 to 154 minutes and interviews from 44 to 128 minutes.

Agency archival information

This portion of the study aimed to examine the last ten years of policy and practice documents (e.g. Annual Reports) from disability service providers participating in *Moving Ahead*. The aim was to extract information that reflected the changes over time in the ethos and practice of agencies that would reflect changing priorities in disability support services. This element of the research experienced unforeseen challenges. Formal annual reports could only be obtained from two non-statutory agencies, and of these, representation was inconsistent across the ten year period in question (2002-2012).

Attempts to obtain a broader range of documentation from agencies which may have sufficed to reflect policy and practice proved similarly challenging. Firstly, it became clear that comparable data could not be sourced across the differing participating agencies. Much of the documentation was informal such as newsletters and promotional material, typically highlighting case studies of personal achievements throughout the year such as participation in Special Olympics and other social or employment activities. Secondly, in order to source the type of material that was envisaged in this portion of the study, a full audit would have been required of agency policy and practices, possibly by managerial interview. This level of investigation was considerably beyond that envisaged for this portion of the study. As a consequence, the limited documentation obtained was used as contextual material for subsequent interviews and focus groups within these agencies but could not be used for the cited purpose of tracking policy and practices.

As an alternative, national level archived material was accessed, notably documentation from National Service Plans developed by the HSE which provide annual and standardised data on policy shifts and implementation. The rationale for this choice was that comparable data was required over time, and that these data could provide insight into external influences bearing on the practices in participating agencies throughout this period.

2.8 DATA ANALYSIS

Both quantitative and qualitative analyses were carried out. During this process, the research team consulted with the project Steering Group for statistical expertise and review of qualitative themes.

Quantitative analysis of surveys

Descriptive statistics were calculated for survey data to identify frequencies, across the group as a whole as well as by region and by type of service. Parametric and non-parametric analyses as appropriate identified whether people differed significantly, depending on the regions or the service type in which they lived.

Qualitative analysis of focus groups and interviews

A constructivist grounded theory approach was used to analyse this large quantum of qualitative data. This approach was selected over the more traditional grounded theory approach (Glaser, 1992, as cited in Bryman, 2008) on the basis that a constructivist grounded approach is appropriate when findings are guided by existing knowledge within the field, and data analysis, while broadly iterative, is also guided by the existing evidence-base. This analysis attempts to go beyond simple thematic analysis to determine how participants and researchers co-construct a shared meaning of the phenomena under investigation, in this case disability services.

The process began with verbatim transcription of all focus group and interview recordings. In total, approximately 29 hours of focus groups and 63 hours of interviews were recorded, 92 hours approximately in total.

A distinct coding process was used for focus group and interview data. Focus group data were manually coded while interview data were coded using computer assisted qualitative data analysis, specifically, NVivo Version 10. The decision to use two distinct types of analysis was based on criticism in the literature where code and retrieval functions within computer assisted tools can result in over-fragmentation of the data and loss of the communication process which is integral to focus groups (Caterall & Maclaran, 1997). For this reason, manual analysis was undertaken for the focus groups conducted in *Moving Ahead.*

The process of coding was both iterative (bottom up) and informed by the research questions and relevant literature in the field (top down). Codes were defined as *'a word or phrase that captures something important about the data in relation to the question, and represents some level of patterned response or meaning within the dataset'* (Braun and Clarke, 2006: p.82). A coding frame was developed, initially for the focus group with individuals with intellectual disability who were the first group to be analysed, and then supplemented as the analyses of other stakeholder groups were undertaken. The two researchers undertaking these analyses worked in tandem to ensure consistency across coding. One researcher then collapsed axial codes, generated from original codes, to a list of themes. A code book and coding frame was then constructed with feedback from some project partners and invited members leading to refinements in the code book. The code book material, based on data from the focus groups was then used to form the initial coding frame for analysis of interviews. To assist in the interpretation of the large volume of data, main themes were presented graphically for discussion by the research team on several occasions. Emerging findings were also presented to the Steering Group to provide assistance in interpretation.

Validation of draft qualitative findings

Validation in qualitative research entails presenting draft findings to a stakeholder group for feedback. In a different region to those under study, themes with anonymised data from four stakeholder groups (direct care staff, family members and people supported and senior agency personnel) were presented to seven senior staff in residential intellectual disability services. The aim was to explore the 'semantic' validity (Krippendorff, 2004) and (b) generalisability (Ryan & Bernard, 2000) of the findings, and to discuss the appropriateness of (c) triangulation (Jick, 1979) of data from these stakeholder groups. S*emantic validity* investigates the degree to which quotes are determined to represent a particular theme. *Generalisability* refers to whether the findings are deemed applicable to other samples of the populations in question (e.g. people with intellectual disability, family, staff). *Triangulation* assess whether information from different stakeholder groups was appropriately combined to broad themes emerging from the data.

To assess the semantic validity, generalizability and triangulation effects of the study, a series of examples from real data generated by *Moving Ahead* was presented to the group. Each example was discussed to determine whether it was appropriately coded, could be deemed to be generalisable, and was triangulated where appropriate. The quotes and themes were semantically validated by the group, although their feedback indicated that overly academic language should be avoided. These quotes and themes were also deemed generalisable and were familiar to those working in the field. Finally, feedback also suggested that triangulation of the findings was ecologically valid, as it reflected the context of service provision in Ireland and the experience of the group.

3. Results: Archival Records

This section presents findings from analyses of two secondary sources of data; existing archival reports and the NIDD database. The aim of these secondary data analyses was to provide a historical context within which data gathered from the two regions could be interpreted.

3.1 REVIEW OF ARCHIVAL REPORTS

The review of archival records aimed to document changes in policy and practice, if any, within participating agencies over a ten year period. As mentioned previously this type of documentation proved elusive. Formal annual reports could be obtained from two non-statutory agencies and representation was inconsistent across the ten year period (2002-2012). Attempts to gather alternative documentation, including online information, proved fruitless for the intended purpose as broader documentation from agencies tended towards promotional literature of best practice in social and sportive activities. It may have been possible to gather information through a full audit of each participating agency's policy and practice, perhaps by interview with management, however such an undertaking was beyond the resources of the study.

The difficulty in sourcing information on advances in policy and practice within individualised agencies raises issues about how informed individuals with intellectual disability and their families may be regarding specific disability service providers. It may be that the current catchment area approach to service provision reduces any competition among providers and consequently this type of documentation is available only between service provider and commissioner. Specifically, this information is captured in schedules under Part 2 of the Service Level Arrangements between commissioners and providers.

As an alternative source of data, national level archival material was accessed for this part of the study from HSE National Service Plans. These plans provide annual information on proposed service delivery, reflecting policy shifts and implementation. They also provide an indication of the impact of Ireland's financial crisis on the delivery of disability services. The information contained in these reports does not address the original aim of this part of the study which was to document changes in policies and practices within specific organisations, but does provide useful information on broader context within which service provision developed in the two case study regions. The next section 3.2 provides detailed information on developments during the latter part of this period. The developments should be considered within the broader national context.

HSE National Service Plans were available from 2005 to 2012. In 2005, HSE state 'services for persons with disabilities seek to enable each individual with a disability to achieve his/her full potential and maximise independence including living as independently as possible'. This aspiration is listed verbatim annually to 2008. Specifically addressing intellectual disability, the 2005 report, and its companion report in 2006, present NIDD data on the number of individuals registered on the database (25,416 for 2005) and a breakdown of those requiring services within the coming year, both day and residential, and those estimated to require services over the following five years.

Targets are identified for the development of new services in 2005, specifically 270 new residential places, 400 new day places and 90 new respite places. Specific commitments are made to enhance specialist services for individuals who present with behaviours that challenge; to open new 'Intellectual Disability Units' (unspecified number); and to meet the cost of a cohort of individuals

move to 'more appropriate placements'. An additional 41 million euro is designated to fund these services 'over and above 2004 existing funding levels'.

Strategic priorities for 2005 include the above development of additional and specialised services. Also prioritised is improved access to services, clearer pathways to care, and strengthened links between statutory and non-statutory services to ensure a continuum of care. Collaboration with mainstream housing and acute health services is advocated. These priorities reflect efforts to support individuals navigate the service landscape, and encourage the use of mainstream services. Other priorities are characterised by efforts to empower individuals with disabilities. Targets here include enhancing consultation and choice for people with disabilities through representation at disability fora, promoting greater involvement in planning and decision making, and supporting advocacy services. A community-based approach to 'ensure integration of individuals into their local communities' is accompanied by a call to re-prioritise resources under the RAPID and CLAR programmes which support community development in designated areas of deprivation and rural areas experiencing substantial population decline respectively.

Key issues for the year ahead include the impact of the Education for Persons with Special Educational Needs Act 2004 (EPSEN); compliance with proposed National Standards for Disability Services and the provision of specialist services for those with high support needs.

The 2005 plan was delivered under the legislative framework of the Health Acts 1947 to 2004 and within the policy context of the larger health system. In the absence of disability specific policies the plan utilises a distinct budget to increase the quantum of existing services.

By 2006, a marginally smaller number of individuals are identified as registered on NIDD (24,917). An additional 73.8 million is allocated 'in respect of funded service developments' within the broader disability services. 39.5m is allocated for intellectual disability and autism services of which 35.9m is for 255 new residential places, 535 new day places and 85 new respite places. 2.2m of this allocation is assigned to meet costs associated with moving individuals to 'more appropriate placements'. There is also mention of capital investment for a new unit in non-acute services which is funded separately from a 60m fund under the auspices of the National Development Plan.

The 2006 plan reiterates a number of the priorities from 2005 including enhanced care pathways, use of mainstream services and the provision of specialist services where required.   New priorities for service delivery focus on increasing manpower within the disability sector through investment in more professional therapy courses, and empowering existing staff through continual professional development opportunities and training on new legislation such as the Disability and EPSEN Acts. Increased collaboration is also prioritised notably between statutory departments; specifically the Department of Justice, Equality and Law Reform in relation to accessing grant aid schemes for voluntary bodies, and the Department of Education and Science in relation to EPSEN. Collaboration is also called for between Statutory Agencies in relation to assessment of need; noting that need encompasses the broader determinants of health, including the provision of housing.

The 2006 plan addresses issues of data management and accountability within disability services. A call is made to refine and develop monitoring systems to record and collate funding information linked to outcomes. Proposals for data monitoring are regularly cited in these annual plans, however the actual implementation of these proposals is unclear. In 2006, The disability databases, NIDD and the National Physical and Sensory Disability Database (NPSDD) are specifically targeted for development, as is the establishment of a minimum data set to monitor service activity on a monthly basis. Arrangements between service providers and commissioners are identified as a 'key issue for the year ahead' following publication of the Comptroller and Auditor General's (2005) report *Provision of Disability Services by Non-profit Organisations.* As noted in Section 1.3 the Comptroller and Auditor

General found extensive administration, service and financial accountability deficiencies and called for greater transparency in financial reporting with funding allocated on the basis of clearly articulated agreements.

The 2006 plan continues the pattern observed in 2005 whereby distinct funding is identified to increase the quantum of existing services. Key priorities are largely responsive to legislative requirements of the Disability and EPSEN Acts, and to the recommendations of the Comptroller and Auditor General.

The 2007 report is the first to acknowledge the National Disability Strategy (NDS; 2004) as providing a guiding framework for the delivery of disability services. NDS aims to support the participation of individuals with disabilities in Irish society through a combination of legislation (EPSEN Act 2004; Disability Act 2005; Citizens Information Act 2007), Sectoral Plans devised by six Government Departments specifically addressing their role in supporting persons with disabilities, and MAIP, a multi-annual investment programme of €900 million covering the period 2006 to 2009. The 2007 Plan specifically notes that NDS builds on an equality framework that *'puts the policy of mainstreaming of services for people with disabilities on a legal footing'* (p.40).

The 2007 report identifies MAIP as the source of funding for much of the recent increases in service provision. MAIP aimed to target 'high-priority disability support services' and is credited in the 2007 report as providing additional capacity in personal assistants, home support, residential, day and respite places. Precise information on MAIP funding has proved elusive in more recent years, notwithstanding Parliamentary debates[9] evidence that MAIP was curtailed during recession. In 2012 the Department of Health acknowledged that the absence of performance data from MAIP led to a lack of clarity regarding *'how agencies used MAIP money for their clients in terms of new services, existing services, financing core deficits funding and additional staff'* (Department of Health, 2012: p.54). This criticism comes despite a commitment in the 2007 HSE National Service Plan to extend the HSE corporate reporting system to integrate financial data from the major disability organisations, a task commenced in 2006 and predicted for completion in early 2007.

The presentation of data on service usage in the 2007 report is altered from previous reports. The number of individuals receiving services within the current year and projected over a five year period is replaced with a 'projected outturn' figure for the preceding year, and a 'target' figure for the current year, a format continued to 2012. The number of additional places to be funded for 2007 mirrors that of 2006; 255 residential, 535 day and 85 respite places under a 41m funding envelop for 'Intellectual Disability'. The budget also covers the transfer of 35 individuals from 'inappropriate settings'. A distinct budget of 15 million is specified in relation to meeting commitments arising from the Disability Act in relation the development of early intervention teams supporting individuals aged 0-5. This investment reflects the approaching deadline of 1st June 2007 for implementation of Part 2 of the Disability Act. Part 2 provides for an independent assessment of need of individuals with a disability and the consequent drawing up of Service Statements. The plan notes the ongoing recruitment of Assessment and Liaison Officers, and the necessity for a complete reconfiguration of Early Intervention Services prior to the implementation of the Act. This reconfiguration is to commence in 2007 for 0-5 year olds, as will plans for a reconfiguration of these services for 6-18 year olds. Staff recruitment to address this reconfiguration had commenced in 2006 and a commitment for continued recruitment is included for 2007.

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[9] Dail Debates 1sst July 2009 available at:
http://oireachtasdebates.oireachtas.ie/debates%20authoring/DebatesWebPack.nsf/takes/dail2009070100124?opendocument&highlight=%20Multi%20Annual%20Investment%20Programme

Other priorities for 2007 include completion of a Strategic Review of HSE Adult Day Services to comprise a full census of HSE funded day services using agreed definitions; implementation of recommendations from the Comptroller and Auditor General report on governance issues; and the completion of a minimum dataset and review of current data information systems within the sector.

By 2008, the crisis in Ireland's economy is reflected in the National Service Plan. A national employment ceiling is reported across the entire health system whereby employment levels in 2008 will not be allowed to grow beyond authorised levels. Any recruitment in 2008 must fall within the national employment ceiling. Staffing levels of 14,727 are cited for 2007 and are projected unchanged for 2008. Cost reductions of 2% are introduced across the health sector, with a proposed saving of 280 million, 120 of which is expected to be realised from cost savings associated with off-patent medications. No further financial information is presented on investment in disability services.

Data is provided on the number of new places provided in the previous year, 175 residential, 420 day and 64 respite but no figures are provided for any proposed increase to the number of places available within the current year. Increases in staff posts are proposed, in total 198 together with 145 from 2007 to 'support service developments', totalling a commitment of 343 new staff posts in residential services over a two year period during a period of economic austerity. The source of funding is likely the Multi-annual Investment Plan (MAIP).

Compliance with Part 2 of the Disability Act is a major focus of the plan. Commitments are made to roll out the service to children 0-5 years and an indicator set to monitor progress is agreed. This age group are also the focus of a reconfiguration of services for those with complex developmental needs. The report notes that the framework document on this reconfiguration is to be implemented 'within available resources'.

Within adult services, two large scale reviews are cited. The review of HSE funded adult day services is due for completion and another review is scheduled to commence examining the situation of an estimated 3,000 individuals living in congregated settings with a view to moving to community-based options.

By 2009, the economic situation in Ireland has deteriorated further; a situation reflected in repeated calls within the National Service Plan for 'doing more' with current resources. Savings of 280 million delivered in 2008 are to be matched by similar savings in 2009 of 250 million across the entire health system, culminating to a target saving of 500 million over the period 2007-2010. A disability budget of 1.5 billion is proposed for the year, as is a 1% reduction in allocations to 'voluntary disability providers'. Staffing levels for 2009 are capped at 16,425 WTE. Interestingly, the report also cites the number of WTE employed as of September 2008 at 15,725. This figure exceeds the projected staffing figure for 2008, cited in the 2007 report, by 1,698.

Information on capital works are introduced in the 2009 report. A total of seven projects are identified including an eight bedded residential facility. The number of individuals supported in this facility falls above that which would later be recommended by the HSE review of congregated settings published in 2011.

Much of 2009 report focuses on the assessment of need programme mandated by Part 2 of the Disability Act. A suite of key performance indicators are agreed to monitor progress, including the number of assessments received (2,597 in 2008), the number commenced (2,044 in 2008) and the number completed (1,036 in 2008). Targets for 2009 are modest increases for assessments received and commenced, while the number of completions is expected to double. The report identifies 140 additional multidisciplinary staff employed in 2008 to meet this demand and a figure of 7.2 million is allocated in 2009 to recruit 90 additional WTE. Developments in adult service provision focus on the

reconfiguration of day services and on agreeing priority findings from the Working Group on Congregated Settings.

Notwithstanding the economic climate, the 2009 report presents evidence of rising staffing levels and investment in infrastructure in the sector. This investment however occurs within the context of reduced allocations to voluntary providers and likely reflects investment from the Multi-annual Investment Plan (MAIP).

The 2010 plan highlights the level of financial cuts across the entire health sector in Ireland. 'Efficiency' savings of 500m were achieved over 2008-2009 and the report comments 'In 2010 we aim to not only repeat this but also introduce additional efficiencies valued at over 400 million'. A commitment is made to deliver 900m in efficiencies 'ahead of our 2007 position'. Contributing to these efficiencies is a reduction of 1,600 WTE throughout the health sector.

For the disability sector, 2% efficiencies are to be implemented 'in line with national parameters'. These efficiencies come on top of 1% efficiencies the previous year and in the context of growing numbers of individuals with intellectual disability registering on NIDD. The disability budget for 2010 is estimated at 1,476 million, reduced from 1,583 million in 2009. For the first time in the National Service Plans, this budget is presented by service type; statutory services receiving a budget of 1,026 million, with the voluntary sector receiving 450 million.

The commitment to deliver an agreed level of service is accompanied by the commentary that day service places and emergency residential needs were substantially met though 'creative use of existing resources'.   Other priorities refer to compliance with Part 2 of the Disability Act, implementation of the reconfiguration of multi-disciplinary services for children, and implementation of *New Directions*, the final report outlining a new reconfiguration of adult day services.

Additional funding of 19.5 million, translated as 215 WTE, is allocated in 2010 to the provision of 100 residential places, 400 day places and 140,000 personal assistant home support hours. The budget line notes 'a proportion of this will be met through agencies which are not part of the HSE headcount'.

Capital investment is detailed for five projects, one of which is the eight bedded 'residential facility' previously cited in the 2009 listing. The remaining four projects include a children's assessment centre, a 60 bed bungalow street-scape, a 30 bed 'residential unit' and a relocation programme. Investment in these larger residential settings seems somewhat contradictory to a 'key result area' in the report which calls for implementation of recommendations from the report of the Working Group on Congregated Settings. While the report was not published until 2011, HSE may have expected that congregated settings supporting 30 to 60 individuals with disabilities would be discouraged. In fact, the Working Group report subsequently recommended than no more than four individuals should be supported under one roof in dispersed community housing.

Data and information infrastructure are represented in calls for the completion of an evaluation of a minimum dataset and the completion of a review of data management systems. The related issue of a lack of information on agreements between HSE and voluntary providers is addressed in a call for the completion of Service Arrangements with all non-statutory providers, and appropriate monitoring of same.

The 2010 report introduces specific targets to facilitate implementation of statutory standards for residential provision in the disability sector; specifically, collaboration between HSE and HIQA to support provider organisations prepare for the introduction of national quality standards for residential settings. An audit of child protection practices is also cited initiated by an eight year enquiry (1999 to 2007) into the Brothers of Charity service in Galway.

The national economic landscape of austerity and efficiency drives continues to be represented in the 2011 National Service Plan. A Public Service Agreement (known locally as the Croke Park agreement) between Government and representatives of public sector staff introduces large scale reductions and redeployment of public sector workers nationwide. The 2011 plan identifies Croke Park as an 'opportunity to further transform and modernise the health services'. Funding restrictions are again in place at 1.8% for disability services, in addition to the 1% and 2% reductions of 2009 and 2010 respectively. A budget of 1,554 million is allocated to disability, down from 1,582 in 2010. The 2010 budget exceeds that forecast in the 2010 report, where a figure of 1,476m is cited. The breakdown of figures by statutory and voluntary sector for 2010 and 2011 costs as presented in the 2011 report reveal a reduction of 0.68% for statutory services and a reduction of 4.8% for voluntary providers.

Additional funding of 10m is allocated for 'priority' services in disability, in this instance addressing demographic pressures in the provision of services. Three capital projects are included in the plan, an update of an existing day centre, and the previously cited 8 bedded and 30 bedded facilities. These proposed developments are prioritised in the same year as HSE publish recommendations from their own Working Group on congregated settings which recommends that no more than four individuals with disability live together under one roof.

The policy landscape for the development of disability services in 2011 includes the National Disability Strategy 2004 with a reference to the awaited *Value for Money and Policy Review* of Disability Services being conducted by the Department of Health. Key priorities in 2011 include conclusion of the Value for Money and Policy Review, the introduction of a resource allocation system based on the assessment of need process, compliance with legislation and quality standards, and ongoing support of reconfiguration to children's therapy services and both adult day and residential services. Data systems continue to be represented with a commitment to conduct a 'scoping exercise' on ICT (information and communication technology).

The final year of review, 2012, continues the drive towards reducing costs. The budget allocation across the entire health sector is described as 'a major challenge to the HSE and comes at a time of signification reform of the public health system'. A reduction target of 750m follows 'two unprecedented years' where 1.75 billion was removed from the health budget. Staffing level reduce by 8,700 since peak employment in 2007.

The allocation for disability services is reduced by 3.7%, 'as a consequence of the impact of efficiency, procurement and targeted pay reduction savings'. This reduction comes on top of cumulative reductions of 4.8% since 2009. The plan proposes that there is 'scope' for achieving efficiencies up to 2% though consolidation and rationalisation of back office costs. Noting that some providers have made greater gains in efficiencies than other, the report states that HSE managers have scope, within the national 3.7% figure, to vary the level of reduction to individual providers on the basis that some services have made significant progress in reducing costs.

Gains in efficiency are linked to the development of new types of service in a number of places throughout the 2012 service plan. Accelerated moves towards individualised and person centred planning are deemed to help achieve efficiencies, particularly for individuals who have a mild or moderate level of disability. Similarly, the new model of service is deemed to further the independence of individualised with disabilities 'in a manner which is efficient and cost-effective'. It may be that the blending of these two concepts within official HSE literature sends mixed messages to the public who may question whether the proposed model of service delivery is driven by a desire to promote quality outcomes, or reduce costs. The report also notes that HSE does not accept sole responsibility for the proposed change programme; 'people with disabilities, their families and carers a multiplicity of agencies, Government and society as a whole' are also identified as being responsible.

Finally, it is somewhat unclear from the report whether the proposed reconfiguration is to be progressed given the comment 'if agreed by Government' in relation to the new model of service provision.

A budget of 1,541 million is projected for service delivery in 2012. The budget presented for 2011, at 1,576m exceeds the projected budget cited in the 2011 report by 22m. Provision is also made for a 1m investment in autism services to address waiting lists for specialist therapies. Only one capital project is identified, an early intervention and assessment unit.

Priorities in 2012 include maximising the provision of services 'within available resources' and ongoing work related to the reconfiguration of children's services, autism services, and both adult day and residential services. All therapeutic services are to be mainstreamed into the community. Legislative and quality standards must be met, including Part 2 of the Disability Act and moves to prepare service providers for the introduction of registration and inspection of residential services. Key result areas for 2012 include much of the territory cited above, and commitments to develop and test a resource allocation system, agree a date for the cessation of admissions to congregated settings, and support 60 individuals to move from congregated settings under the auspices of GENIO, a charitable trust promoting new types of service delivery.

The 2012 report can be characterised as an ambitious plan given the scope of reconfiguration and the severe reduction in funding. The report reflects the significant impact of the economic situation and was followed by further cuts across the entire health sector of 721m in 2013, with a proportional cut in funding of 1.2% in disability services.

In combination, the HSE National Service Plans provide a useful insight into the changing fortunes of disability service delivery from 2005 to 2012. The time period captures what is undisputedly a unique moment in the history of the Irish state. The economic crisis plunged the nation into a level of debt that could only be addressed through a loss of national sovereignty; the price for securing a stable income stream from Europe.

Early national service plans identify funding in excess of annual budgets for new service places. Quality outcomes such as choice, representation and advocacy pepper the text. Inclusion of marginalised groups living in rural or deprivation areas is addressed. Investment in staff development and training to meet legislative requirements are listed as key actions. These priorities stand in stark contrast to latter years where a series of major reconfigurations are proposed within the context of severe and cumulative financial cuts. Despite the environment of austerity, additional monies were sourced for new staff, notably linked to Part 2 assessments and the development of multi-disciplinary services for children, and investment in capital programmes. Approval of some of the larger capital projects does however seem contradictory to policies towards more individualised community-based supports.

Of particular interest for *Moving Ahead* is the suggestion in the final national plan, 2012, that the proposed new model of service may not be agreed by Government despite being clearly outlined in the HSE's own reviews of adult day and residential services, and articulated in detail in a policy review prepared for the Value for Money and Policy Review (Department of Health, 2011). It is also interesting to note the linking of cost efficiencies with this new model of service, a strategy that may blur stakeholders' views on the rationale behind the proposed reconfiguration.

Overlaying these national planning data are trends in service delivery extracted from NIDD by McConkey et al (2013). Recall that these data reveal that the pace of change throughout the country was variable, with some regions introducing considerable reform, others less. The next section explores these NIDD data in detail for the two case study regions in *Moving Ahead*, charting progress

to 2012 to determine if the trends observed by McConkey and colleagues to 2009 remain apparent by 2012.

Data was sought from the NIDD, through a formal request process, on demographic characteristics and residential circumstances of adults, defined as persons aged 20 years or over, living in the two former Health Board regions selected for participation in *Moving Ahead*.

At the start of the study, the most recent available NIDD information was for 2011, and this section presents these baseline data to describe adults supported in these two regions. The section concludes by examining data over a five year period (2007-2012) to match that presented from the HSE National Service Plans.

The NIDD regional data presented here use the same geographical unit of analysis as that employed by McConkey et al (2013) in their examination of regional differences from 1999 to 2009. This unit of analysis is the former health board region; in existence in 1999 but since disbanded in a reconfiguration of health services.   Nationally, eight such regions were responsible for service provision, whether directly or commissioned to non-government organisations. Two of these regions provide the case studies for this study.

Comparison with national data

In 2011, these two regions accounted for 21% of all adults aged 20 years and over registered nationally on NIDD (n=17,406). Proportionally, twice as many adults were registered from Region 1 (n = 2,561) as in Region 2 (n = 1,102). **Figure 3.1** presents the proportions of individuals receiving different types of residential supports nationally, and in Region 1 and Region 2.
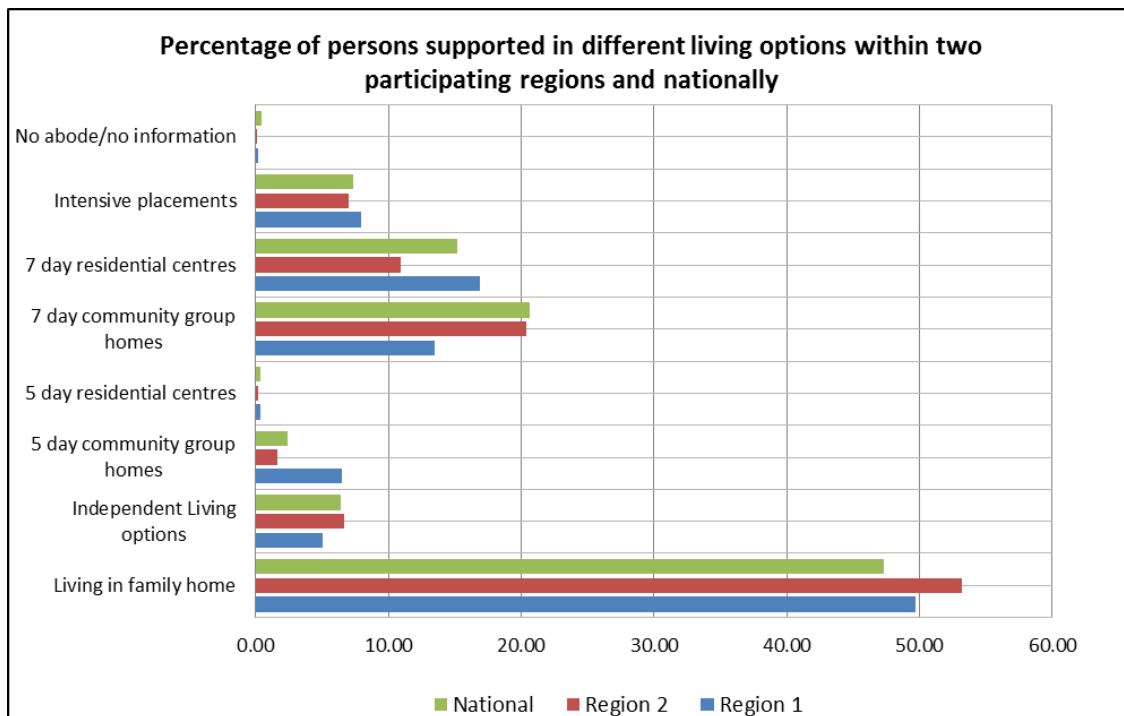
Figure 3.1: Percentage of persons supported in different living options within the two regions.

Compared against national figures, both regions have greater proportions of people supported in the family home. Region 1 was distinguished by greater provision of 7 day residential centres and considerably greater use of 5 day community group homes than observed nationally. This region was less likely to provide 7 day community houses and independent living options than that provided nationally. In contrast, Region 2 was distinguished from the national data by providing less 7 day residential centres and less 5 day community group homes. The provision of 7 day community group homes and independent living options in this region were similar to those observed nationally.

The actual numbers of people supported in these living arrangements is presented in Table 3.1. Similar proportions of adults over 20 years were observed in both regions for those living in the family home (approx. 50%), independent living options (5-6%) and intensive placements (approx. 7%) which comprise nursing homes, mental health community services, psychiatric hospitals and intensive placements for persons with behaviours that challenge or profound or multiple disability. The numbers of these individuals receiving additional respite is small, at approximately 5-6% in both regions.

Table 3.1: Comparison of residential living arrangements in the two regions

Residential setting	Region 1		Region 2		Difference	
	n	*%*	*n*	*%*	*n*	*%*
Home with parents, siblings, other relatives, foster care	1273	49.7%	586	53.2%	687	3.5%
Independent/semi-independent living	128	5.0%	73	6.6%	55	1.6%
5 day supports – community group homes	166	6.5%	18	1.6%	148	4.9%
5 day supports – residential centres	9	0.4%	2	0.2%	7	0.2%
7 day supports – community group homes	345	13.4%	225	20.4%	120	7.0%
7 day supports – residential centres	433	16.9%	120	10.9%	313	6.0%
Other full time intensive placements	203	7.9%	77	7.0%	126	0.9%
No fixed abode or no sufficient information	4	0.2%	1	0.1%	3	0.1%
Region total registered on NIDD	**2561**	**100%**	**1102**	**100%**	**1459**	**0%**
Adults receiving residential supports in the region	**1284**	**50.1%**	**515**	**46.7%**	**769**	**3.4%**
Adults in residential services receiving respite supports	**74**	**5.7%**	**28**	**5.4%**	**46**	**0.3%**

Differences were observed in the proportions of individuals supported in 5 day and 7 day residential options. While 5 day residential centres were rarely used in either region (by less than 0.5%), individuals were four times more likely to use 5 day community group homes in R1. Patterns of 7 day residential provision revealed that people in R1 were less likely than those in R2 to be supported in 7 day community group homes but were more likely to be supported in 7 day residential centres. These data strongly suggest that the main driver of the disparity in living arrangements between the two regions was the numbers of persons supported in 7 day residential centres. It may be that the mere presence of these residential centres within a region encourages their use; in their absence, community-based supports would need to be sourced.

By combining the data to categories of community-based (independent living arrangements and community group homes) and congregated type living arrangements (residential centres and other intensive placements) as per the definitions used by McConkey et al (2013), a clear pattern emerges whereby Region 1 had similar proportions of adults supported in community-based and congregated services, while Region 2 supported greater numbers in the community (Table 3.2). The disparity is likely to reflect the practices of specific agencies in each region.

Table 3.2: Numbers of adults by region receiving community-based and congregated supports in 2011

Type of residential service	Region 1		Region 2	
Community-based services	639	49.8%	316	61.4%
Congregated services	645	50.2%	199	38.6%
Total	**1284**	**100%**	**515**	**100%**

Demographics of people supported in the two regions

The NIDD data regarding adults with intellectual disabilities receiving residential supports in the two regions illuminate their characteristics in terms of gender, age, level of diagnosed intellectual disability and presence of any physical and/or sensory disabilities. For these profiles, it is important to note that differences between the regions are negligible (Table 3.3). The gender proportions of adults supported are nearly equal in both regions. Proportions of age groups do not differ between the two regions: in both, just over half of people supported are aged 40-59 years, fewer than a third are aged 20-29 years and just under a fifth are aged 60 years and over.

Table 3.3: Demographic characteristics of adults with intellectual disabilities in the two regions

Demographic characteristics	Region 1		Region 2	
	n	%	n	%
Gender				
Male	698	**51.6%**	243	**47.2%**
Female	586	**48.4%**	272	**52.8%**
Age				
20-39 years	381	**29.7%**	152	**29.5%**
40-59 years	671	**52.3%**	263	**51.1%**
60 years +	232	**18.1%**	100	**19.4%**
Level of ability				
Mild intellectual disability	291	**22.7%**	119	**23.1%**
Moderate/Severe/Profound intellectual disability	969	**75.5%**	396	**76.9%**
Not known	24	**1.9%**	0	**0%**
Co-morbid disability				
Physical and/or sensory disability	545	**42.4%**	220	**42.7%**

Similarly, there was little discernible difference in terms of diagnosed levels of ability of adults registered on the NIDD and availing of residential supports across both regions, where nearly one-quarter had a reported mild level of intellectual disability and three-quarters had a moderate, severe or profound disability. Caution should, however, be applied regarding interpretations of this latter very broad category, as proportions of these levels of ability typically differ a great deal. For example, for the full national population of 27,324 people registered on the NIDD in 2011, 33.3% had a mild level

of disability, 39.8% moderate, 14.9% severe, 3.6% profound, and 8.4% were not verified. This level of detail was not available in the present analyses. Finally, in both regions, just over two-fifths of adults with an intellectual disability registered on the NIDD had at least one co-existing physical and/or sensory disability.

The NIDD data therefore indicate that there is, demographically, little variation between the regions in terms of the adults with intellectual disability supported by residential services. As differences were observed between the proportions of people supported in different types of residential accommodation between the two regions, Tables 3.4 through to 3.7 further explore this issue. They outline the demographic features of adults supported in the two regions in 2011 within the type of residential setting they lived in, and indicate differences that are of note in the context of the goals of deinstitutionalisation.

Looking to the age profiles of people supported in different types of accommodation in both regions in 2011, it can be seen in Tables 3.4 and 3.5 that in Region 1, nearly one in ten people aged 20-29 years were supported in residential centres; in Region 2 in this age group, fewer than one in twenty people aged 20-29 years lived in residential centres. Region 2 also supported proportionally more than twice as many people aged over 60 years in community group homes compared to Region 1.

Table 3.4: Percentage of adults in Region 1 living in each type of setting by age group

	Independent/ Semi-independent n = 128	Community Group Homes n = 511	Residential Centres n = 442	Other full-time services n = 203	Total Residential Services N = 1284
20-29 years	2.9%	13.1%	9.3%	4.4%	**29.7%**
40-59 years	5.5%	22.7%	15.5%	8.5%	**52.3%**
60 years +	1.6%	4.0%	9.7%	2.9%	**18.1%**
	-	-	-	-	**100%**

Table 3.5: Percentage of adults in Region 2 living in each type of setting by age group

	Independent/ Semi-independent n = 73	Community Group Homes n = 243	Residential Centres n = 122	Other full-time services n = 77	Total Residential Services N = 515
20-29 years	4.5%	14.4%	4.3%	6.4%	**29.5%**
40-59 years	8.2%	24.3%	13.8%	4.9%	**51.1%**
60 years +	1.6%	8.5%	5.6%	3.7%	**19.4%**
	-	-	-	-	**100%**

Looking to identified levels of support needs within each type of residential support (Tables 3.6 and 3.7) regional differences can also be identified. For example, of those living in community group homes, in Region 2 11.5% have low support needs whereas in Region 1, 41.5% have low support needs. Similarly, in Region 2, 42% of those in community group homes have high support needs compared to 20.9% in Region 1. This suggests that in Region 2 agencies are supporting people with higher support needs in community group homes compared to Region 1.

Table 3.6: Percentage of adults in Region 1 living in each type of setting by level of ability

Level of support	Independent/ Semi-independent (n = 128)	Community Group Homes (n = 511)	Residential Centres (n = 442)	Other full-time services (n = 203)	Total Residential Services N = 1284
Minimum	18.8%	3.7%	0.7%	1.0%	**3.7%**
Low	7.0%	41.5%	3.2%	1.5%	**18.5%**
Moderate	0.8%	33.7%	5.4%	1.0%	**15.5%**
High	0.8%	20.9%	90.7%	96.1%	**54.8%**
Intensive	0.0%	0.2%	0.0%	0.5%	**0.2%**
N/A[10]	72.7%	0.0%	0.0%	0.0%	**7.2%**
	100%	100%	100%	100%	100%

Table 3.7: Percentage of adults in Region 2 living in each type of setting by level of ability

Level of support	Independent/ Semi-independent (n = 73)	Community Group Homes (n = 243)	Residential Centres (n = 122)	Other full-time services (n = 77)	Total Residential Services N = 515
Minimum	17.8	2.9	4.1	3.9	**5.4**
Low	1.4	11.5	0.8	3.9	**6.4**
Moderate	0.0	42.0	1.6	9.1	**21.6**
High	0.0	42.0	92.6	46.8	**48.7**
Intensive	0.0	1.6	0.8	13.0	**2.9**
N/A[11]	80.8	0.0	0.0	23.4	**15.0**
	100%	100%	100%	100%	100%

Day services

In both regions, the greatest proportion of adults with intellectual disabilities avails of day services in activation centres or adult day centres. These are described in the NIDD Information Manual as "day centres for adults who need ongoing care, training, and development in a wide range of skills. Because of the nature of their disabilities, many of these people may not be capable of participating in open or sheltered employment or in special vocational training programmes" (NIDD Information Manual, 2012, p. 11). This trend may reflect the fact that three-quarters of those registered on the NIDD database have a moderate, severe or profound disability.

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[10] This refers to adults with intellectual disability who do not require supports, and therefore level of support is not applicable

[11] This refers to adults with intellectual disability who do not require supports, and therefore level of support is not applicable

Table 3.8: Primary day activities engaged in by adults with intellectual disabilities in the two regions

	Region 1		Region 2	
	n	%	n	%
Activation centre/Adult day centre	469	36.5%	213	41.4%
Multidisciplinary support services	91	7.1%	71	13.8%
Sheltered work centre	257	20.0%	66	12.8%
Special high support day service	225	17.5%	15	2.9%
Other	242	18.8%	150	29.1%
Total	1284	**100%**	515	**100%**

It is interesting to note some pronounced differences between regions in day services availed of by adults with an intellectual disability. Special high support day services are reported to be offered to proportionately six times as many individuals in Region 1 as in Region 2, and multidisciplinary support services, availed to proportionately twice as many in Region 2 as in Region 1. The reason for these discrepancies is unclear because, as noted above, the diagnosed level of ability of supported people did not differ notably across the two regions.

Patterns of moves of residential accommodation in the two regions, 2007-2012

Finally, in the context of a policy push for deinstitutionalisation in Ireland, it is particularly interesting to identify any region-level changes taking place in the proportions of people supported in particular types of settings. The following tables provide data as recorded on the NIDD for accommodation changes in the two regions for the most recent 5-year period for which data were currently available during the study period, i.e., 2007 to 2012.[12]

Table 3.9 reveals that in the 5 years to 2012, almost all adults with intellectual disabilities registered on the NIDD in Region 1 remained in their current setting (91.04%). Moves that did take place were from 'other' full-time high-support services, where 5.2% of people supported moved to community group homes; and from residential centres, where 5.3% of people supported moved to community group homes. These are likely to reflect small moves towards deinstitutionalisation. At the same time, however, a similar proportion of people supported in community group homes, 5.2%, moved into residential centres. This therefore suggests that this region has not even achieved the 'slow and tentative drift' reported nationally by the Value for Money Report (Department of Health, 2012) but rather a 'stalling' of deinstitutionalisation.

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[12] Note that in these rows, percentages may not sum to 100. This reflects records where people died, left a service, or for whom there was insufficient information.

Table 3.9: Change of residential setting 2007-2012: Percentage of adults with intellectual disabilities in Region 1

2007 Settings (below) N = 2431	2012 Settings (across) N = 2248				
	Home	Independent/ Semi-independent	Community Group Homes	Residential Centres	Other full-time services
Home N = 1142	90.5%	2.8%	4.1%	1.4%	1.1%
Independent/Semi-ind. N = 122	4.1%	89.3%	4.1%	1.6%	0.8%
Community Group Homes N = 480	0.8%	1.0%	90.8%	5.2%	2.1%
Residential Centres N = 457	0.4%	0.7%	5.3%	92.6%	1.1%
Other full-time services N = 212	0.5%	0.5%	5.2%	1.9%	92.0%

The stasis in Region 1 contrasts strongly with the pattern of moves for adults supported in residential accommodation in Region 2 (Table 3.10). The proportion of individuals who remained in situ over the period 2007-2012 is 76.74%, a considerably lower figure than the 91.04% reported in Region 1. Of those who moved within this time period, a dramatic move to community-based accommodation can be seen: nearly half of people supported in residential centres (47.4%) in Region 2 in 2007 had moved to community group homes by 2012, as had nearly a third (29.9%) of those in other, high-support, full-time services.

Table 3.10: Change of residential setting 2007-2012: Percentage of adults with intellectual disabilities in Region 2

2007 Settings (below) N = 961	2012 Settings (across) N = 963				
	Home	Independent/ Semi-indep.	Community Group Homes	Residential Centres	Other full-time services
Home N = 473	89.4%	3.8%	3.4%	0.6%	2.7%
Independent/Semi-ind. N = 50	0.0%	94.0%	0.0%	0.0%	6.0%
Community Group Homes N = 217	1.8%	2.3%	88.5%	3.7%	3.7%
Residential Centres N = 154	0.6%	0.0%	47.4%	50.6%	1.3%
Other full-time services N = 67	3.0%	1.5%	29.9%	4.5%	61.2%

Taken together, these data suggest that the patterns of moves – with strong regional differences – identified by McConkey et al (2013) for the decade 1999-2009 were still persisting up to 2012, with Region 2 continuing to achieve a strong drive towards deinstitutionalisation, and Region 1 making little progress.

Taken in the context of the information gleaned from a review of HSE National Service Plans, the NIDD data indicate that throughout a period of major financial constriction, with a cumulative call for funding cuts to the tune of 10.5%, Region 1 maintained a strong program of reform in residential provision.

These data, while clearly informative, speak only to the numbers of individuals living in different accommodation types. They do not address whether quality outcomes differ for individuals living in dispersed community housing or congregated accommodation. Nor do they address whether quality outcomes differ for individuals living in each region. These issues are addressed in the next section.

Summary findings from Results of Archival Records

Review of HSE National Service Plans from 2005 to 2012 revealed a period of considerable economic turmoil nationwide.

The period is characterised by services responding to legislative requirements of EPSEN 2004 and National Disability Act 2005 and compliance with HIQA standards in residential settings.

Major reform is introduced covering early intervention, multidisciplinary supports, autism services, adult and day residential services.

Impact of financial crisis is apparent from 2008 from which period cumulative cuts in funding allocations of 10.5%, and restrictions on employment levels are introduced.

Evidence from McConkey et al (2013) indicates that progress towards community living differed markedly in the two case study regions from 1999 to 2009, on the cusp of the economic crisis.

Baseline data from NIDD at the commencement of *Moving Ahead* from 2011 continues this disparity.

Despite little apparent difference in the demographic profile of the full population of people in receipt of intellectual disability services in these regions, service provision differs markedly by region.

Individuals living in Region 1 are more likely than those in Region 2 to live in residential centres at a younger age, more likely to live in an intensive placement as they age, and more likely to be supported in a community group home if classified as having low support needs.

Access to multidisciplinary support services is twice as likely in Region 2.

The pattern of movement to different residential settings indicates that while one in four individuals moved in Region 2 during this time period, just one in ten individuals did so in Region 1.

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4. Results: Survey of People with Intellectual Disability

This section presents findings from a survey of people with intellectual disability supported in a variety of living arrangements in the two participating case study regions. Seven service agencies participated in the survey. Of the six agencies originally enrolled in the study, one organisation, a HSE statutory agency in Region 1 was unable to participate in the survey. A replacement organisation supporting individuals in campus-based style accommodation in Region 1 was invited to act as a suitable replacement organisation. An additional small non-statutory agency in Region 2 was also invited to participate in the survey. In total, seven organisations participated; 3 in Region 1 (2 X large non-statutory agencies and 1 smaller non-statutory agency) and 4 in Region 2 (1 HSE statutory agency, 1 large non-statutory agency and 2 smaller non-statutory agencies).

Administration of the survey required considerable effort and goodwill on the part of the agencies. The survey process required agencies to liaise with the research team to prepare anonymised sampling frames; support direct support staff obtain consent or family agreement on behalf of all participants (the research team could not complete this task under ethical obligations); support participants complete the surveys; and engage in any follow up checking requested by the research team. For each agency a nominated staff person was identified as a contact person to liaise with the research team. Fully accessible and easy to read information and consent materials were provided for all participants to maximise individuals' understanding of what participation in the survey would entail.

A total of 229 individuals with intellectual disability were invited to participate in the survey. The sampling frame comprised full sample listings for small organisations or by stratified sampling (without replacement) capped at 60 individuals for larger organisations.

In total, 136 individuals with intellectual disability participated in the survey, yielding a response rate of 59.4%. The response rate from Region 1 (45.7%) was lower than that from Region 2 (73.9%).

Of the final sample of 136 individuals, 40% (n = 54) lived in Region 1 and 60% (n = 82) Region 2. These participants lived in 74 different settings, which reflected most types of support offered to people with intellectual disabilities in Ireland: institutions or residential campuses, clusters of service agency housing in the community, dispersed community group homes, dispersed independent living with tenancies, and intensive placements for people with multiple or profound disabilities or people who present with behaviours that challenge.

The survey was designed to be as accessible as possible, and keyworkers were asked to report on the level of engagement by the supported person in completing the survey. Nearly half (45.6%; n = 62) reported that participants engaged to some degree, although 15 of those were reported to have engaged 'rarely'. For the rest of participants (n = 74, 54.4%), surveys were completed by proxy or information about level of engagement was not provided.

The degree of participation is particularly relevant where questions elicited the views of people with intellectual disabilities; for example, on their mood in recent weeks, their satisfaction with their friendships, and their satisfaction with the place they live. For these items findings are only reported from those who engaged 'mostly' or 'somewhat' with the survey (n = 47, 34.6% of the full sample).

The settings in which participants lived were categorised as either 'congregated' or 'dispersed-community' housing. The definition of the HSE 2007 *Working Group on Congregated Setting*s (HSE, 2011) was used to guide these definitions. HSE describes *any setting with ten or more supported people* as congregated. Therefore if ten or more people with disabilities live in one house, the setting is designated as congregated, even if it is physically located in the community.

This definition is in fact less stringent than the model for supports recommended by the same Working Group in their 2011 HSE report, *Time to Move on from Congregated Settings* which defined dispersed housing as '*scattered through ordinary residential neighbourhoods'*, supporting a maximum of *four* people with a disability. This definition is mirrored in the subsequent Department of Health's 2012 definition of 'independent living' as a *'domestic-style house or apartment in the community, where the number of residents may range from one to four and the neighbouring houses are occupied by members of the wider community'* (p.140). The current status may therefore be described as one where service providers are encouraged to reduce the numbers of individuals sharing accommodation, albeit that nine individuals supported within a community group home may be criticised as in breach of the spirit of the recommendations.

Given a lack of finality on these recommendations, specifically noting that HSE had yet to agree a date for the cessation of admissions to congregated settings in the 2012 National Service Plan, it is fair to propose that the focus for service providers may be more likely to facilitate those living in settings of ten or more to move to the community, or to move to smaller settings in the community, albeit not necessarily to settings of four or less. Of importance in these moves to smaller community settings is whether they comply with the notion of 'dispersed', described by HSE and the Department of Health as scattered throughout the community where neighbouring houses are occupied by members of the wider community.

For the purposes of the current survey, the following working definitions were applied:

A setting was defined as **congregated** if it met any of the following three criteria:

1. A residential or campus setting **or**

2. A community setting that could be considered 'clustered' on the basis that two or more properties on the same road supported people with intellectual disabilities from the same agency **or**

3. A house supporting ten or more people irrespective of location.

A setting was defined as **dispersed community** if it met the following two criteria:

1. A dispersed dwelling in the community **and**

2. A house supporting fewer than ten people in the community

Using this categorisation, of the 74 settings 37 were found to be *congregated*, supporting 61% participants (n = 83); 37 *dispersed community* settings supported 39% participants (n = 53). These were distributed differently in the two regions in the study (Table 4.1): in Region 1, almost all participants lived in congregated settings, whereas in Region 2, fewer than half lived in congregated settings. This regional difference was significant, χ^2 (1) = 29.17, p <.001 (SR -2.8).

Table 4.1: Participants from each region living in congregated and dispersed community settings

| | Participants (N = 136) | | | |
| | Congregated (n=83) | | Dispersed Community (n=53) | |
	N	% of region	n	% of region
Region 1 (n = 54)	46	85.2%	8	14.8%
Region 2 (n = 82)	37	45.1%	45	54.9%

The small number of individuals classified as living in 'dispersed community' settings in Region 1 (n=8) has implications for the statistical analysis of the survey. The aim was to conduct statistical analysis that would identify differences in demographics, quality outcomes and other variables simultaneously between regions (Regions 1 and 2), and between setting type (congregated and dispersed). The possibility of undertaking these analyses with such a small number in one group was discussed with a member of the Steering Group with expertise in statistics. On advice, the data from the survey are analysed independently by setting type and then region or are presented descriptively where appropriate.

Setting Types

The setting types, as classified by participants, are presented in the pie chart below. Nearly one third of the sample lived in a residential campus or centre, or lived in an intensive placement for individuals with high support needs. The remainder of the sample (68%) lived in community group homes or independent living options. These findings suggest that over two thirds of the sample lived in community-based options.

Further analysis however, including follow up phone calls to participating agencies, indicated that a number of dwellings located in the community should in fact be defined as 'congregated' based on the working definition used in the present survey: these dwellings either housed more than ten persons and/or reached the criterion of a community cluster given their close proximity to other dwellings managed by the same agency. Examples of dwellings which might traditionally have been deemed community-based being classified as 'congregated' included community group homes supporting ten or more individuals, community group homes located on a road with other properties owned by the same agency, independent living options annexed onto larger properties owned by the agency, and independent living options based in residential campus settings. In Region 1 this was the case for the 26 participants (17 living in community group homes, 6 in supported living, and 3 in an intensive placement). In Region 2 this was the case for 17 participants (9 living in community group homes and 8 in supported living).
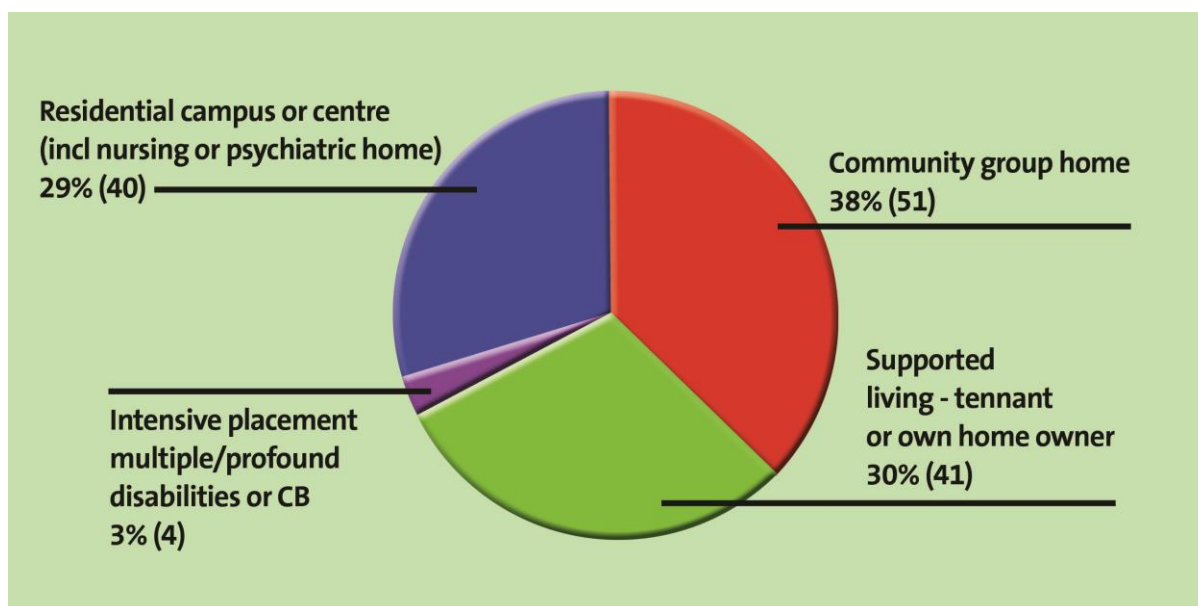
Figure 4.1: Pie Chart of reported living arrangements

Table 4.2 presents the breakdown of these residential living options within the two regions; also presented is their designation as 'congregated' or 'dispersed community' setting using the working definitions of the current study. Almost one third of participating dwellings in Region 1 (31.5%) were community group homes which reached the criteria for congregated settings either on the basis that they were not located in dispersed settings, or on the basis that more than ten individuals lived in the dwelling. Similarly, approximately one in ten individuals in both regions identifying with the independent living model was also found to reach the above criteria.

The finding suggests that the classification of 'community' and 'congregated' as used in NIDD and employed by McConkey et al (2013) may in fact underestimate the scale of reform required nationally to achieve compliance with recommendations of the Congregated Settings Working Group and the Value for Money and Policy Review.

Table 4.2: Current residence by region and setting type						
	Congregated		**Dispersed Community**		**Total**	
	n	%	n	%	n	100%
Region 1	*n = 46*		*n = 8*		*n = 54*	
Residential campus/ centre; nursing, psychiatric	20	37.0%	0	0%	20	37.0%
Community group home	17	31.5%	5	9.3%	22	40.7%
Supported living – tenant or own home owner*	6	11.1%	2	3.7%	8	14.8%
Intensive placement – Multiple/profound or CB	3	5.6%	1	1.9%	4	7.4%
Total Region 1	46	85.2%	8	14.8%	54	100.0%
Region 2	*n = 37*		*n = 45*		*n = 82*	
Residential campus/ centre; nursing, psychiatric	20	24.4%	0	0%	20	24.4%
Community group home	9	11.0%	20	24.4%	29	35.4%
Supported living – tenant or own home owner*	8	9.8%	25	30.5%	33	40.2%
Intensive placement – Multiple/profound or CB	0	0%	0	0%	0	0%
Total Region 2	37	45.1%	45	54.9%	82	100.00%

*where supported living tenants are represented as living in congregated settings, this is because they are living in community clusters

In terms of representation of participants by agencies, Table 4.3 shows that all participants from the large NGO in Region 1 were supported in congregated settings, and that all participants from one smaller NGO in Region 2 were supported in dispersed community settings. The other five NGOs and State agencies taking part supported people in both congregated and dispersed community settings.

Table 4.3: Current residence by region and agency type

	Congregated		Dispersed Community		Total	
	n	%	*n*	*%*	n	*100%*
Region 1						
Large NGO (1)	12	22.2%	0	0%	12	22.2%
Small NGO	13	24.1%	3	5.6%	16	29.6%
Large NGO (2)	21	38.9%	5	9.2%	26	48.1%
Total Region 1	**46**	**85.2%**	**8**	**14.8%**	**54**	**100.0%**
Region 2						
Large NGO	16	19.5%	17	20.7%	33	40.2%
HSE	15	18.3%	2	2.4%	17	20.7%
Small NGO (1)	6	7.3%	13	15.9%	19	23.2%
Small NGO (2)	0	0%	13	15.9%	13	15.9%
Total Region 2	**37**	**45.1%**	**45**	**54.9%**	**82**	**100%**

4.2 DEMOGRAPHICS AND SUPPORT NEEDS

This section presents findings on participants' age, gender, level of ability, support needs, engagement in behaviours that challenge and duration in current living arrangement.

Age

To compare age across setting type and regions in this study, non-parametric analysis was chosen and Mann-Whitney comparisons were carried out. No difference was observed in the age of those living in congregated (Md=61.9, n=68) and dispersed community housing (Md=52.3; n=47) U = 1330.00, z = -1.525, p = 0.12. A difference was observed in the age of those living in the two different regions (U = 1248.00, z = 2.042, p=0.41) with those living in Region 1 being younger (Md=50.50, n=48) than those living in Region 2 (Md=63.37).

Gender

Chi Square analyses were used to examine the distribution of participants by gender. No difference was found between the proportions of men and women availing of congregated and dispersed community living arrangements (χ^2 =2.27, df=1, p= 0.13). Regional differences were apparent with Region 1 supporting proportionally greater numbers of men (χ^2 =15.44, df=1, p= 0.0001).

Level of Ability

Level of ability was self-reported on the survey using the classifications 'mild', 'moderate', 'severe' and profound'. This information was not recorded for 13 participants. These data were analysed using Chi Square analyses which included a Fishers' Exact correction for small numbers in expected cells. Level of ability was found to differ for those living in congregated and dispersed community settings (χ^2 =15.69, df=4, p= 0.002). In line with expectations those living in dispersed community settings were proportionally more likely to have an intellectual disability classified in the mild range. No difference was observed between the level of ability of the samples participating in the two regions (χ^2=2.49, df=4, p= 0.65).

Support Needs

Level of ability may be considered a rather blunt tool from which to assess an individual's capacity to engage in independent lifestyles. More recently, the focus is placed on the differing levels of support required for all levels of individuals to enhance quality of life (American Association on Intellectual and Development Disability, 2010). A brief Support Needs Scale, used in an extensive population-based study in the UK (Emerson, Malam, Davies & Spencer, 2005) was used to measure the support needs of individuals in this survey. This measure indicates the level of support individuals require to complete day to day tasks such as 'getting up in the morning', 'filling in a form', and 'paying money into a bank or post office'. Two additional items were added to the scale on the advice of Steering Group members; 'using public transport' and 'using the phone'. For this sample of 133 valid respondents, the scale was highly reliable with a Cronbach's alpha of .954. Scoring for all items on the Support Needs Scale is presented in Table 4.4.

Table 4.4 Level of Support Need for full sample (n=133 responses)

Support needed to complete task	On own		A bit of help		A lot of help		Someone to do it	
	n	%	n	%	n	%	n	%
Get dressed	69	50.7%	30	22.1%	14	10.3%	23	16.9%
Put on shoes	78	57.4%	21	15.4%	5	3.7%	32	23.5%
Shower/bath	39	28.7%	31	22.8%	32	23.5%	34	25.0%
Order in cafe	37	27.2%	28	20.6%	15	11.0%	54	39.7%
Drink cup of tea	114	83.8%	8	5.9%	1	0.7%	12	8.8%
Wash clothes	22	16.2%	15	11.0%	13	9.6%	86	63.2%
Make sandwich	41	30.1%	22	16.2%	14	10.3%	58	42.6%
Fill in a form	5	3.7%	12	8.8%	19	14.0%	100	73.5%
What's on TV	29	21.3%	14	10.3%	10	7.4%	82	60.3%
Bank, Post Office	17	12.5%	20	14.7%	15	11.0%	84	61.8%
Make appointment	14	10.3%	12	14.7%	6	4.4%	104	76.5%
Public transport	16	11.8%	15	11.0%	31	22.8%	72	52.9%
Using the phone	32	23.5%	16	11.8%	13	9.6%	75	55.1%

This information is presented graphically in Figure 4.2 below. In general, individuals reported requiring most assistance with administrative tasks such as form filling, making appointments and using banking facilities.
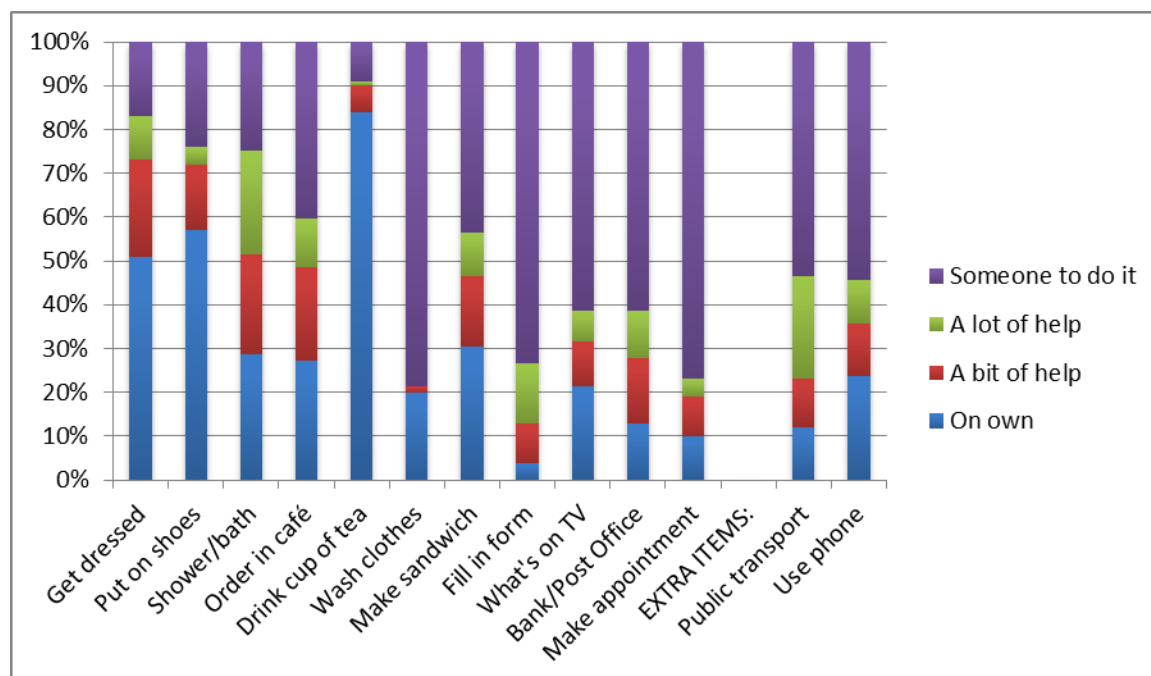
Figure 4.2: The Support Needs Scale (Emerson et al, 2005) scores for full sample including added public transport and phone use items.

Statistical comparisons were undertaken between the support needs scores of those living in the different type of settings (congregated and dispersed community housing) and also between those living in the two participating regions of the study. Mann Whitney analyses revealed a similar pattern to the findings for level of ability. Those living in congregated settings had significantly higher support needs (Md = 33, N = 82), than those living in dispersed community settings (Md = 27, N = 51), U = 1525.00, z = -2.62, p = .009). No regional difference was reported between the support needs of those living in Region 1 (Md = 32, N = 54) from participants in Region 2, (Md = 30, N = 79), U = 2098.00, z = -.161, p = .872.

Behaviours that challenge

The Modified Overt Aggression Scale (MOAS; Kay, Wolkenfeld & Murrill, 1988) was used to establish levels of engagement in behaviours that challenge. This scale is completed by a direct support staff on behalf of each individual.

Table 4.5 below presents the numbers of individuals reported to engage in these behaviours in the full sample. Only those who completed the scale in full are included in these analyses so sample sizes may be less than the full 136 sample.

Table 4.5: Numbers of participants engaging in Behaviours that Challenging as measured by MOAS

Verbal N = 132	n	%
None	99	75.0%
Shouts, curses mildly, makes personal insults	23	17.4%
Curses viciously, is severely insulting, has temper outbursts	4	3.0%
Impulsively threatens violence towards others or self	5	3.8%
Repeatedly or deliberately threatens violence to others or self	1	0.8%
Total number reporting any verbal aggression	**33**	**25.0%**
Property N = 128		
None	105	82.0%
Slams door, rips clothing, urinates on floor	12	9.4%
Throws objects down, kicks furniture, defaces walls	5	3.9%
Breaks objects, smashes windows	5	3.9%
Sets fires, throws objects dangerously	1	0.8%
Total number reporting any property aggression	**23**	**18.0%**
Auto N = 128		
None	102	79.7%
Picks or scratches skin, pulls hair out, hits self without injury	9	7.8%
Bangs head, hits fist into walls, throws self onto floor	10	7.0%
Inflicts minor cuts, bruises, burns, or welts on self	7	5.5%
Inflicts major injuries on self or attempts suicide	0	0
Total N reporting any auto aggression	**26**	**20.3%**
Physical N = 128		
None	103	75.7
Makes menacing gestures, swings at people, grabs at clothing	9	6.6
Strikes, pushes, scratches, pulls hair of others (without injury)	10	7.4
Attacks others, causing mild injury (bruises, sprains, welts, etc)	4	2.9
Attacks others, causing serious injury	2	1.5
Total N reporting any physical aggression	**25**	**19.5%**

Verbal aggression was the behaviour most commonly engaged in across the full sample; damage against property least so. In particular behaviours such as 'shouts, curses mildly, makes personal insults' were endorsed almost twice that of any other behaviour.

The figures presented above are not mutually exclusive: the same individuals for example may appear under verbal aggression and physical aggression. Taking unique cases only, 52 individuals (38.2%) within the sample were identified as engaging in one or more of these categories of behaviour.

Total scores were computed on the MOAS scale and weighted according to the severity of each behaviour; verbal aggression behaviours received a weighting of one, aggression against property a weighting of two, auto-aggression (self-injurious behaviour) a weighting of three, and physical aggression to others a weighting of four. Different scoring techniques may be used with MOAS; the method used here is that recommended by the American Academy of Paediatrics. This scoring method aims to reflect not only the presence but also the severity of these behaviours.

Mann Whitney analysis found no difference in the weighted MOAS scores of participants between those living in congregated (n=72, Md=63.97) and those living in dispersed housing (n=51, Md=59.23) U = 1,694, z = -0.84, p=0.40. Analysis by region did reveal a difference. Individuals living in Region 1 (n=50; Md=69.22) were more likely to be reported as engaging in these behaviours (n=50, Md=69.22) than those living in Region 2 (n=75, Md=57.05) U = 1,464, z = -2.15, p=0.03.

Length of time since moving from family home and at current residence

Most participants, 83% (n = 113), moved from their family home over 10 years ago; this applied across regions and setting types. In terms of how long they had lived in their current setting, participants in the survey fall broadly into two distinct groups. Nearly half (48%) have lived at their current location for 1-5 years, whereas 40% have lived in their current location for 10 years or more.

The length of time participants had been at their current residence was also explored by region and setting type. In the context of existing policy for deinstitutionalisation in Ireland, it is interesting to note the recent moves in the two regions (see Table 4.6). In Region 1, most participants who had moved in the last 5 years moved to congregated settings (23 of 30; 76.7%). In Region 2, in contrast, most participants who moved in the last 5 years moved to dispersed community settings (28 of 36). Overall, therefore, this indicates that in Region 1, most supported people moved to congregated settings; the opposite is the case for Region 2.

Table 4.6: Length of time at current residence

	Congregated		Dispersed Community		Total	
Region 1	N=46	%	N=8	%	N=54	%
5 years or fewer	23	42.6%	7	13.0%	30	55.6%
6-9 years	2	3.7%	0	0.0%	2	3.7%
10 years or more	18	33.3%	1	1.9%	19	35.2%
Not recorded	3	5.6%	0	0.0%	3	5.6%
Total Region 1	**46**	**85.2%**	**8**	**14.8%**	**54**	**100.0%**
Region 2	N=37	%	N=45	%	N=82	%
5 years or fewer	8	9.8%	28	34.1%	36	43.9%
6-9 years	4	4.9%	5	6.1%	9	11.0%
10 years or more	24	29.3%	11	13.4%	35	42.7%
Not recorded	1	1.2%	1	1.2%	2	2.4%
Total Region 2	**37**	**45.1%**	**45**	**54.9%**	**82**	**100.0%**

The demographic information gathered on behalf of participants indicated that those living in Region 1 were more likely that those in Region 2 to be male, younger and to be reported as engaging in behaviours that challenge. Level of intellectual disability and the support needs of participants did not differ by region, but did by setting type; those in congregated settings had lowers levels of intellectual disability and higher support needs than those living in dispersed housing.

The previous regional pattern of disparity in moving towards community living is reflected in participants' current living arrangements. Those living in Region 1 were less likely to move to dispersed housing in the community in the previous five years than their counterparts in Region 2.

4.3 HEALTH STATUS AND USE OF HEALTH SERVICES

This section provides information on health status, presence of long-term illness or disability, use of medication, self-reported mood, level of engagement in exercise and use of health care facilities.

Health status last year
Almost all participants, 88%, were reported to be either in very good (39%, n = 53) or fairly good (49%, n = 67) health within the previous year. Chi square with Fisher's exact test revealed that health

status did not differ between those living in congregated or dispersed housing (χ^2=5.194, df=2, p= 0.76). No difference was reported in health status by region (χ^2=4.021, df=2, p= 0.21).

Long-term illness or physical disability

Notwithstanding reports of overall very good or fairly good health, almost 8 out of 10 participants (79%, n = 107) reported a long-term illness or physical disability. The difficulties and illnesses reported in the surveys were as follows: 36.0% (n = 49) had epilepsy; 36.0% (n = 49) had difficulty speaking; 25.0% (n = 34) had a *Mental health difficulty*; 22.1% (n = 30) a *Physical disability and* 21.3% (n = 29) a diagnosis on the autism spectrum. In addition, 11.0% (n = 15) had hearing difficulties and 9.6% (n = 13) had difficulties with vision. Finally, 19.9% (n = 27) had *other long-term illnesses such as* swallowing difficulties/dysphagia; diabetes (n = 4) and asthma (n = 3); other illnesses, cited by one participant each, were cancer, heart disease, Alzheimer's and Parkinson's.

In light of the small numbers of individuals who reported that they did not have a long-term illness or disability (e.g. just one person in a congregated setting in Region 2, and just one person in a dispersed community property in Regin1), no statistical analyses were undertaken by setting type or region. These data are presented descriptively in Table 4.7 below. The proportion of those with long-term illness or disability living in congregated settings is markedly higher for people in Region 1 (70.4%) when compared with Region 2 (42.7%): similarly, over twice as many people with long-term illness or disability live in dispersed housing in Region 2 than Region 1.

Table 4.7: Percentage of participants reporting a long-term illness or physical disability

	Congregated		Dispersed Community		Total	
Region 1	n	%	n	%	N	%
Yes	38	70.4%	7	13.0%	45	83.3%
No	4	7.4%	1	1.9%	5	9.3%
Don't know/ no response	4	7.4%	0	0.0%	4	7.4%
Total Region 1	46	82.5%	8	14.8%	54	100.0%
Region 2	n	%	n	%	N	%
Yes	35	42.7%	27	32.9%	62	75.6%
No	1	1.2%	16	19.5%	17	20.7%
Don't know/ no response	1	1.2%	2	2.4%	3	3.7%
Total Region 2	37	45.1%	45	54.9%	82	100.0%

Prescribed medication

In total, nearly two-thirds of the sample had a prescription for an epilepsy (AED) or anti-psychotic medication (n = 84; 61.8%). Over a third of participants had prescriptions for epilepsy medication (38%, n = 51), and for anti-psychotics (40%; n = 55). Of those taking AEDs, 15.7% (n=8) did not have a diagnosis of epilepsy. Of those taking anti-psychotic medication, 45.5% (n=25) did not have a mental health condition.

As can be seen in Table 4.8, very few of these prescriptions were as PRN only; almost all were either a regular prescription alone or a regular prescription with a PRN.

Table 4.8: Epilepsy and anti-psychotic medication

	Regular prescription		PRN		Both		Total	
	n	%	n	%	n	%	n	%
Epilepsy	28	20.6%	2	1.5%	21	15.4%	51	37.5%
Anti-psychotic	34	25.0%	3	2.2%	18	13.2%	55	40.4%

Prescribing patterns for anti-psychotic medication were explored by setting type (χ^2=1.51, df=1, p=0.28) and by region (χ^2=3.397, df=1, p= 0.065). No differences were reported, albeit that the regional differences were approaching statistical significance with higher proportions of people on these medications in Region 1. Prescribing patterns for epilepsy medication were similar in different types of settings (χ^2=1.09, df=1, p= 0.296) and within the two regions (χ^2=0.205, df=1, p= 0.651).

Self-reported mood

Self-reported mood over the past month was only analysed from surveys where participants had participated 'mostly' or 'somewhat' in the survey. Very few people reported experiencing low mood in the past month: just five in total. These data may reflect high levels of mood among respondents, or may reflect a combination of acquiescence (Rapley & Antaki, 1996) or the 'gratitude factor' observed for some people with intellectual disabilities who receive health and social services (Gregory et al 2001). Given the very low numbers of endorsements in this scale, no further analyses were undertaken.

Exercise

Participants were asked if they engaged in any exercise that made them 'sweaty or out of breath'. Just over one third of responders (n=46; 36.2%) stated that they engaged in this level of exercise. Chi square analysis revealed that individuals living in dispersed community housing were more likely to participate in exercise that those in congregated settings (χ^2=5.358, df=1, p= 0.025). No differences were observed in exercise levels between the two regions (χ^2=0.474, df=1, p= 0.491).

Additional analyses were undertaken to determine if the difference in exercise activity between individuals living in congregated and dispersed settings may be due to the fact that people who live in congregated settings have a more severe level of intellectual disability. Mantel-Haenszel test of condition independence revealed that, after controlling for level of ability, there is no evidence of a difference in exercise between setting types (χ^2=2.035, df=1, p= 0.154). This means that people's level of ability, and not their setting, was the main driver of their engagement in exercise.

Health service utilisation

In Figure 4.3 levels of health service utilisation in the last 12 months in the full sample can be seen. The figure provides detail on whether these health services were provided within disability services, within generic community services, or across both.
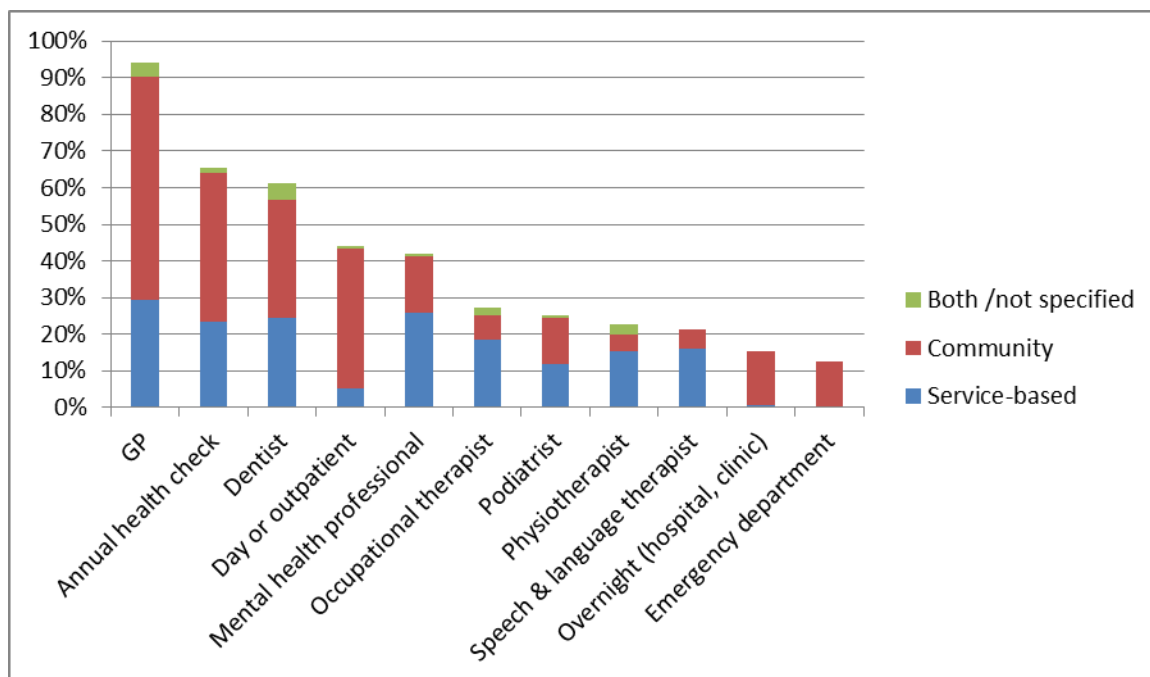
Figure 4.3 Levels of health service utilisation across the full sample of participants

Nearly all participants had visited a GP in the preceding year, and most of these GP visits were made to a community service. Just under two-thirds of participants had had an annual health check and had seen the dentist – also mostly in community-based services, though this difference was less pronounced. Mental health professionals, occupational therapists, physiotherapists and speech and language therapists were more likely to be accessed through a disability service provider than in the community, suggesting that these services in particular will need to increase supply as more people with intellectual disabilities move from congregated to community settings and avail of community-based health care.

The next tables identify the types of health services endorsed by participants in the different regions, by type of setting and by whether the service they used was community or service based; the figures are not mutually exclusive as some individuals may have used more than one type of health service in the previous year.

Table 4.9: Health service utilisation in congregated settings

Health service utilisation	Congregated				Dispersed Community			
	Community health care		Service-based health care		Community health care		Service-based health care	
	Region 1	Region 2	Region 1	Region 2	Region 1	Region 2	Region 1	Region 2
Overnight (hospital, clinic)	8	7	0	1	1	0	0	0
Day or outpatient	25	12	2	5	2	0	0	0
Emergency Dept.	5	4	0	0	2	0	0	0
GP	24	15	20	14	6	2	2	4
Dentist	16	8	20	5	4	4	4	4
Physio, OT, SLT[3]	3	1	27	33	3	3	3	7
Podiatrist	6	4	9	5	4	5	5	2
Annual health check	14	12	21	7	4	2	2	2
Mental health professional	5	6	20	6	1	5	2	4
Total	106	69	119	76	27	21	18	23

Caution must be exercised in the interpretation of these data. They are not mutually exclusive individuals so proportional comparisons cannot be determined. General trends indicate that for people living in congregated settings, health services cluster around GP services, dentistry and annual health check services provided both within services and located in the community, and community-based day or outpatient services. Specialist services such as physiotherapy, occupational therapy and speech and language therapy are more likely provided by specialist disability services. For those living in dispersed housing, the main trends appears to be a lack of use of more medicalised services such as overnight hospital care, outpatients and emergency services. These patterns may reflect trends of higher proportions of long-term illness and disability among individuals living in congregated settings.

Summary

In combination, these health data indicate that many participants are in good health and report positive self-mood, however it is possible this may reflect some level of acquiescence. High numbers of participants have co-morbidities: epilepsy, speech difficulties and mental health difficulties being most common. Perhaps unsurprisingly, these co-morbidities are more common among individuals living in congregated settings. Those living with these co-morbidities in dispersed housing are more likely to live in Region 2. Prescriptions for epilepsy and mental health difficulties were present for two-thirds of the sample; prescribing patterns did not differ by region or setting type. Exercise levels did differ by setting type, however this was found to be related to people's level of ability rather than the type of setting where they lived. Finally, health service utilisation indicated that individuals in congregated settings tend to rely on some community-based services (e.g. GP and dentistry) and on some disability specific services (e.g. therapeutic services). Individuals in dispersed housing showed lower usage of more medicalised services possibly reflecting their lower likelihood of long-term illness.

The following quality outcomes were measured: life satisfaction, social engagement, exercising choice, contact with family and friends and advocacy.

Life satisfaction

A set of 11 questions explored personal life satisfaction drawn with permission from Bergström et al's (2013) scale for satisfaction with life among people with mild to moderate intellectual disabilities living in community residences. The scale measures satisfaction with life, housing, meals and recreational activity and reports. The scale has reported Cronbach's alpha .70 and was calculated at .60 in the present study.

This section of the survey could not be completed by proxy, as studies have shown that proxy responses on quality of life may differ from the perspectives of individuals with intellectual disabilities themselves (Janssen, Schuengel & Stolck, 2005). The responses analysed were from 47 people whom keyworkers stated had been involved 'mostly' or 'somewhat' in completing the survey.

Table 4.10: Self-reported personal life satisfaction ratings for those who 'mostly' or 'somewhat' engaged completing the survey (n=47*)

	Good		In between		Bad	
	n	%	n	%	n	%
… the place you live	44	93.6%	3	6.4%	-	-
… your neighbours	41	87.2%	5	10.6%	-	-
… how you get along with neighbours	35	74.5%	10	21.3%	-	-
… food during week	39	83.0%	8	17.0%	-	-
… your food at weekends	42	89.4%	1	2.1%	1	2.1%
… your in-between meals	39	83.0%	4	8.5%	-	-
… your leisure time	39	83.0%	5	10.6%	1	2.1%
… your life	38	85.1%	9	14.1%	-	-
… being who you are	40	85.1%	4	8.5%	1	2.1%
… how you feel in your body	37	80.4%	9	19.6%	-	-
… the support and help you receive	45	95.7%	1	2.1%	-	-

*some respondents chose not to endorse some items – replacement values of the average score for the scales were employed.

The scoring for participants who self-reported on personal life satisfaction reveals very high levels of satisfaction with support received and the settings where individuals live. These high satisfaction rates are common among individuals with intellectual disability and, as previously noted, they may reflect acquiescence and/or gratitude to service providers. Given such strong endorsement it is perhaps unsurprising that no difference (U=232.50; z=-0.74, p=0.46) was reported between the ratings endorsed by people living in congregated (n=19; Md=25.76) and dispersed community settings (n=28; Md=22.80), nor was any difference reported (U=218.50, z=-0.29, p=0.76) between those living in Region 1 (n=14; Md=23.11) and Region 2 (n=33; Md=24.38).

Social Engagement

Participants were asked about their engagement in a variety of social activities over the previous month; these are listed in Table 4.11.

Most participants (over 80%) had gone shopping or gone out for a meal in the last month. Nearly two-thirds had been to the hairdresser and just over half had been to the pub. Other activities engaged in

somewhat less frequently were playing sport, going to the cinema, going to the library, and watching sport.

Individuals who live in dispersed community settings (n=53; Md=82.22) were more likely to engage in these activities (U=1472.50; z=-3.286; p<001) than individuals in congregated settings (n=83; Md=59.74). No differences (U=2087.00; z=-0.572; p=.57) were reported between those living in Region 1 (n=54; Md= 70.85) and Region 2 (n=82; Md=66.95)

Table 4.11 Engagement in activities in the community In last month (N = 136)

		yes	With staff	With friends
	n	% of participants engaging in activity	n	n
Shopping	115	84.6%	58	2
Meal	112	82.4%	45	4
Hairdresser	83	61.0%	45	4
Pub or club	70	51.5%	28	5
Play sport	56	41.2%	37	3
Cinema	49	36.0%	22	5
Library	17	12.5%	10	1
Watch sport	17	12.5%	37	3

The survey also asked participants to specify the companions with whom they had undertaken these activities. As can be seen in the table, across the entire sample there is marked contrast between individuals' engagement in activities accompanied by staff, and activities engaged in with friends.

Choice

Participants were asked two items about opportunities to exercise choice. Both items referred to finance; whether people exercised choice in how much money they spent each week, and whether they exercised choice in the types of things they purchased.

Just over a third of people exercised choice in how much they spent each week (n=48, 35.3%). Initial analysis suggested that people living in congregated settings were less likely (n=76, Md=55.45) than those in dispersed housing (n=49; Md=74.71) to exercise choice in how much they spent (U=1288.00, z=-3.45, p<.001). A Mantel Haenszel test, was conducted to see if the difference in exercising choice was influenced by the fact that people living in congregated settings had lower levels of ability. The test revealed that the difference remained even after controlling level for level of ability (χ^2=3.501, df=1, p= 0.061). This means that the settings where people live have an influence on their ability to exercise choice

No differences were reported (U=1761.00, z=-0.872, p=0.38) between choice in weekly spending for those living in Region 1 (n=53; Md=60.23) and Region 2 (n=72; Md=65.04).

Nearly two-thirds of participants were reported to exercise choice in the things they wanted to buy (n = 82, 60.3%). People living in congregated setting (n=75; Md=54.57) were less likely have a choice in the things they wanted to purchase (U=1242.50, z=-3.710, p=.0001) than people living in dispersed housing (n=49; Md=76.64). This difference was maintained when level of ability was taken into account (χ^2=6.25 df=1, p= 0.012). This means that even though people in congregated settings are more likely to have severer levels of intellectual disability than people living in dispersed housing, they don't have as many opportunities to exercise choice in the things they want to buy even when their

level of ability is taken into account. The difference in exercising choice is related to the place where they live.

No difference was found in choice of purchasing (U=1816.50, z=0.279, p=.78) for people living in Region 1 (n=51; Md=61.62) and Region 2 (n=73; Md=63.12)

Contact with family and friends

Regular contact with family and friends is deemed an important indicator of quality of life. A minority of individuals in the study had no know relatives (n=4) or have family but had no current contact (n=3).

Table 4.12 Contact with family and friends in previous six months

Contact with family in last 6 months		N = 129	
	Come to see you	22	17.1%
	Visited them	39	30.2%
	Mix of both	63	48.8%
	Other/Don't know	5	3.9%
Contact with friends in last 6 months		N = 92	
	Come to see you	8	8.7%
	You visited them	10	10.9%
	Mix of both	37	40.2%
	Other/Don't know	37	40.2%

Chi square analyses were used, with Fisher's exact test, to see if contact with family and with friends differed for people living in different types of settings, and for people living in different regions. No differences were reported for people living in congregated and dispersed housing (χ^2=3.271, df=3, p= 0.0.367). Neither was any difference reported between people living in Region 1 and people living in Region 2 (χ^2=5.529, df=3, p= 0.126). The high proportion of 'don't know' or 'other' responses for contact with friends in the last six months may reflect the influence of staff in supporting individuals to complete this section. It may be that staff are more attuned, or place more priority on family contact than friendships.

Advocacy

Participants were asked to identify if they had an independent advocate, that is, an advocate who was not connected with their service provider.

Over one third of respondents (n=46; 36.5%) reported that they had access to an independent advocate. No difference was found between their representation among people living in congregated settings (χ^2=1.10, df=1, p= 0.294), or between people living in Region 1 when compared with Region 2 (χ^2=1.291, df=1, p= 0.259). It is interesting to note that this question was endorsed as 'don't know' or left blank by 24 (17.6%) participants.

Summary

In combination, the findings on quality outcomes indicate that people in living in congregated settings experience lower levels of social engagement in the community and reduced levels of exercising choice when compared with their counterparts living in dispersed housing. Life satisfaction, levels of contact with family and friends and access to an independent advocate did not differ between setting

types. No differences were observed for life satisfaction, social engagement, choice, advocacy and contact with family and friends for people living in the two different regions. These findings indicate that quality outcomes are not impacted by region, but are by the type of setting where a person lives. In all cases where differences in settings were observed, better quality outcomes were experienced by people living in dispersed housing.

4.5 STAFF PRACTICES, STAFFING AND COSTS

The information on staff practices, staffing levels and costs were obtained on a distinct three page survey administered to staff at the same time as they received the survey on the person they supported. The aim of the second questionnaire was to focus on the place where the person lived, who they lived with, and what staffing supports were available.

A total of 74 surveys were returned on behalf of the 136 individuals participating in the study, one for each setting where participants lived. The disparity in figures is due to the fact that it was possible for more than one person in a setting to participate in the survey. In one large congregated setting, for example, 13 people participated in the survey.

Challenges arose in the interpretation of this settings survey due to large amounts of missing data. There was no information on 18 surveys (24.4%), for example, for a question which asked whether the same organisation who owned the property provided the social support for individuals living there. Similarly, information on staffing levels was poor. In 17 cases, no information was provided on the number of WTE direct support staff working in the property (23.1%).

Attempts to examine staff practices were similarly hampered. A question asking if people who lived in the property shared transport to their work or daily activity was not answered on 24 surveys (32.4%). Given the large amounts of missing data, any analyses of these data would be unreliable.

The lack of reliable information on this survey is regrettable given the amount of time and effort spent by staff completing these surveys and by the research team in administering the surveys. The lack of information cannot be categorised in terms of a poor response rate as a survey was returned on all participating settings. Rather the difficulty arose with the completion of the surveys, a task asked of keyworkers supporting each participating individual. It may be that the information being requested was unknown to keyworkers. Information from the pilot study, for example, indicated that the questions on staffing levels needed to be simplified, yet despite these amendments, the surveys were returned incomplete. The likelihood that this information was unknown is supported by the fact that for some settings more than one survey was returned, as different staff members completed the survey on behalf of different participants who lived in the same setting. By comparing the data on the same setting, returned in two separate surveys completed by two different key workers, it became apparent that information on staffing levels and staffing practices did not tally. This disparity strongly indicates that the information requested was unknown to those who completed the survey.

In an effort to address this challenge, each agency was phoned to provide basic information on their participating settings. This information has been presented at the beginning of Section 4.1 above. To collect more detailed data would have essentially meant conducting the entire survey once again by phone; likely with someone more senior to keyworkers. This undertaking was beyond the resources of the study.

The challenges experienced in this part of the survey, while disappointing, are informative. While the level of missing data was a clear sign of unreliable data, the disparities in information returned by different staff members on the same settings suggests that keyworkers may be ill informed about

some of the managerial issues, such as staffing and practices, in the residences they support. The robust data submitted on the survey of individuals supported within these residences suggest that the staff were more than willing to cooperate fully in survey.

Summary findings from Results of Survey of People Supported in different Living Arrangements

Participants and settings:

• 136 individuals participated in a survey that gathered information on their own characteristics and their living circumstances.

• More people lived in Region 2 (n=82; 60%) than Region 1 (n=54; 40%) and more people living in congregated settings (n=83; 60%) than in dispersed community housing (n=53; 39%).

• Definitions differed from the classification of 'congregated' and 'dispersed community' settings as a number of individuals who identified on their survey as living in community-based settings met the criteria for congregated settings used in this study: they supported more than ten people and/or they lived in close proximity to other houses supporting people with disabilities owned by the same agency.

Demographic information revealed:

• People who lived in congregated settings had higher supports needs and lower levels of intellectual disability than people living in dispersed housing

• People who lived in Region 1 were more likely to be male, younger, engage in behaviours that challenge, and have moved to a congregated setting in the last five years when compared to people living in Region 2.

Health information revealed:

• Most people were reported to be in good health and good mood – however this pattern is often reported for individuals with intellectual disability and may reflect an acquiescence bias.

• Most people (80%) had a long term illness or physical disability.

• People who lived in congregated settings were more likely than people living in dispersed housing to have a long-term illness or disability; exercised lower levels of choice in how they spent their money, and tended to avail of more medicalised services and therapeutic services delivered by disability agencies.

• Few differences were found on health matters between people living in the different regions: those who lived in Region 1 who had a long term illness or disability were more likely than their counterparts in Region 2 to live in a congregated setting.

Quality outcome information revealed:

• Most people reported high levels of life satisfaction – again, the issue of possible acquiescence should be noted.

• For most people social activities occurred in the presence of staff, far less so than with friends.

• Contact with family and friends did not differ by setting or region but a noted trend was the high 'don't know' response for contact with friends. This may reflect staff involvement and prioritisation in supporting family contact.

• People who lived in congregated settings were less to engage in social activities and to exercise choice.

• Quality outcomes were not influenced by region; any differences were related to the type of setting where an individual lived.

Staffing practices, levels and possible costs:

• The information received on staffing practices and levels was deemed too unreliable to use for analysis; as a consequence costs based on staffing levels could not be determined.

• The lack of information on staffing is likely a consequence of keyworkers being uninformed about the broader management of the properties where they work as information supplied on the people they support was deemed robust.

5. Results: The Perspective of People with Intellectual Disability

This section presents findings from five focus groups conducted with adults with intellectual disability who were using a spectrum of residential services ranging from institutional care through to independent living. Three focus groups were hosted in Region 1; located in a HSE service, a large non-statutory service and a small non-statutory service. Just two focus groups were conducted in Region 2; one each in a large and small non-statutory service. The omission of a HSE service in Region 2 was based on the recommendation of senior management at this organisation who stated that a focus group could not be facilitated due to age and high support needs of the people supported. The views of people with high support needs were encouraged and represented at other focus groups, mostly through the support of accompanying staff.

Findings from these focus groups are presented in four sections below: experiences of residential services; perspectives on different types of living arrangements; facilitators and barriers to community living; and evidence of any differences in opinion depending on which region and which type of living arrangement supported the person with intellectual disability.

5.1 EXPERIENCES OF RESIDENTIAL SERVICES

A wide variety of residential options were represented through the participants' current and previous engagement with disability services. Many had experienced more than one type of residential living arrangement and this variety was peppered throughout their discussion. Those without experience of a particular type of living arrangement typically spoke of the experience of friends or others in the same agency, or of their own personal aspirations and preferences around these models.

Experiences of changing residential supports

Most of the participants had experience, current or past, of living in the community; typically either in community group homes or in community-based cluster arrangements of houses or hostels. Two other groups were also distinguished, albeit to a lesser degree. One group identified as recently moving to independent living options. The second group, in sharp contrast, were those who described how most of their adult life, and onward into old age, had been spent in locations segregated from the community. These participants lived in institutions or in clusters of housing within the campus of a service provider.

> I've lived here for 44, 45 years now, for donkey's years and I'm 64 now. And my birthday is next month, on 6th October, I'll be 65. Next month on Sunday.

> Well I'm here 23 years. I like living here.

For most, change was a familiar concept. Some of those who were now living in the community had moved from congregated settings. Others were travelling in the opposite direction; as higher support needs emerged, largely related to ageing or ill-health, these individuals were informed they could no longer be appropriately supported in the community and were moved back to non-community settings. The lack of continuity in their place of residence may arguably be imposed by disability organisations rather than freely chosen. What is less arguable is that many participants described the incapacity of organisations to support those with higher support needs in the community.

Satisfaction

Most participants expressed satisfaction with their current living arrangement. This reflects findings from the *Moving Ahead* survey presented in Section 4.4 indicating high levels of satisfaction from people with intellectual disability living in the two regions.

There was one clear exception to this trend. Those living in institutional settings who had started preparations to move to the community complained about the pace of change. Some of this group had recently trialled community-living and understood their permanent move was imminent:

> Well we are going out to the community. We'll be in a house downtown and it's nearly ready now, just to go into it. The furniture and all is there.

There was a palpable sense of frustration at the length of time they were expected to wait for these new arrangements to be organised.

> How long more do we have to wait? […] It's been very unfair to wait so long. *Facilitator: How long have you been waiting for?* Nearly 2 years.

These findings suggest that some people with intellectual disability register their dissatisfaction contrary to a body of research that suggests they tend towards acquiescence. It may be that the focus group environment provided an atmosphere where individuals felt more empowered to complain, or it may be that this group were unconcerned about any retribution of complaint as their support staff may have felt equally frustrated at the lengthy delay.

Summary

The findings of these focus groups should be interpreted in light of the varying experiences participants had of different living arrangements. For some individuals, living arrangement changed across the lifespan from congregated to community, for others the reverse pattern as ageing needs could no longer be accommodated in the community. A distinct group were those who had spent their lives in institutional care, some of whom were soon to move. While most individuals expressed satisfaction with their living arrangements, it was this latter group who complained about the delay they experienced in moving to a new life in the community.

5.2 PERSPECTIVES OF ADULTS WITH INTELLECTUAL DISABILITY ON LIVING ARRANGEMENT OPTIONS

Visual representations were developed of four of the most common type of living arrangements supporting people with intellectual disability in Ireland. These are presented below.

Participants in all focus groups, including people with intellectual disbility, family and staff, were asked their views on these four types of residential living arrangements. These options were deemed to represent the most commonly availed of residential support options in Ireland.

Definitions for these types of living arrangements were standardised across all focus groups to permit comparisons.

Congregated settings were defined according to the definition used in the HSE report on Congregated Settings (Health Service Executive, 2011) of a dwelling where ten or more people with disabilities live under the same roof. Participants were reminded that this definition spanned from large institutional settings in segregated locations to group homes dispersed in the community which supported ten or more individuals.

The second type of living arrangement presented to participants was clustered living arrangements, a specific type of congregated living which has been the focus of considerable debate within the disability sector (Emerson et al, 2000; Mansell & Beadle-Brown, 2009).

Clustered living arrangements were described as dwellings clustered on the sites of former or current institutions and cluster developments in the community, where a number of houses supporting people with intellectual disability are located in close proximity.

The community group home was the third model presented to participants. This was defined as a fully staffed house located in the community where typically three to six people with disabilities live. These houses are dispersed within the community so neighbours do not have intellectual disability.

Finally, independent living was defined as people having greater levels of choice and control over their supports. Participants were informed that independent living does not necessarily refer to living alone, rather to exercising choice in where and with whom one lives; community group homes are deemed incompatible with independent living (European Network on Independent Living)[13]. In other jurisdictions, independent living is supported by the use of personal assistants as opposed to salaried staff from disability agencies, but this system has yet to be introduced in Ireland for people with intellectual disability. As currently implemented in Ireland, independent living for people with intellectual disabilities usually refers to one or more people with intellectual disability renting a property as distinct from those owned by a disability agency, and receiving staff support as and when needed. The separation of property and social support equates to the notion of supported living employed in the UK (Mansell and Beadle-Brown, 2009).

Participants were told that variation exists in these definitions and that they were welcome to suggest alternative definitions. In fact, participants with intellectual disability did deviate from these definitions, notably when talking about independent living. This issue will be discussed further below.

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[13] http://www.enil.eu/policy/

Congregated Settings

Participants from just one focus group lived in a congregated setting (excluding clustered arrangements) at the time the focus groups were conducted. Experiences of congregated living extended beyond this group; many of those now living in the community had previously lived in these settings. The commentary from individuals currently living in these settings is presented first, mindful that feedback from this group is particularly relevant given the large cohort of individuals identified by HSE who will be moved from these settings to community living in the coming years (Health Service Executive, 2011).

Some residents in congregated settings were satisfied with their living arrangement. Others, while noting positive characteristics of the setting, expressed mixed or ambiguous views about it:

> I like in [*name of institution*] but very happy to go to the community […] I had me good times here in [*name of institution*] and they've done a lot for me as I say. And I'll be happy to go to the community, and then like, on the other hand, I'd miss [*name of institution*].

> **[Facilitator: And what's good, Michael, about living here? What's the good points?]** The food is good. Everything is good. Nothing. You take what you get. You won't get everything. You take what you get.

Only those currently living in congregated settings identified positive aspects to the nature of the support provided. Much of this commentary referred to having their physical needs looked after:

> We're very well looked after. Clothes and everything in the morning.

> Tea towels and everything like that. They're all very high clean. Very high clean. […] they collect the dirty laundry and takes it away to [*name of town*] the house keepers go down and collect their own stuff for the wards. They're lovely clean towels and clean bed clothes and everything like that.

> The rooms are lovely. I like the rooms. We have our own rooms.

Although the balance of positive commentary focused on physical aspects of care and the facilities, social support from staff was emphasised by one participant who would shortly be moving to the community:

> They gave me great confidence in myself in everything. They put me into different activations and everything. They put me into different things. They put me into [*name of day centre on campus*], into the choir and everything. They'd take you out for your supper. They'd take you out in the car for spins to the supermarkets and things like that you know? If it was your birthday you'd get a cake, they'd get a cake for you for your birthday and they'd , you know, little things like that you know?

Participants living in the community expressed little positivity about congregated settings. No positive commentary was generated about the support provided in these settings rather their sole positive comment was that congregated settings may provide a more social environment as people would have 'lot of company'. The vast bulk of their feedback was negative.

This negative feedback was distinguished by being far more emotive in tone that criticisms of other types of living arrangements. Some participants who had lived in these settings in the past vehemently expressed a desire not to return, and some who had no direct experience had only negative comments about this type of support. The following quotes give a flavour of the emotive nature of some the comments:

> I think it's very wrong, like.

I think it's cruel like. It's cruel.

I was dying to get out of that place.

The criticism of congregated settings by people with intellectual disabilities generated the following three themes; rigidity and institutionalised nature, unpleasant environments and overcrowding.

In commenting on the rigidity and institutional nature of congregated settings, participants spoke of overly regulated environments dominated by rules and early bed times:

It's too structured

There's probably more rules involved in a congregated.

The environment was described by many as unpleasant. A number of participants spoke specifically about disrupted sleep. The vivid memories recalled many years later by participants now living in the community suggests their experiences of institutional care live long in their memories. One participant who had moved in the 1980s from an institution to a community group home could still recall sleep being disturbed by night lights which were lit to facilitate other residents using the bathroom.

The red lamps. We have them over here in the building and we lived over beyond in what do you call it, [*name of service*] Do you know, so it's kind of harsh too that the lights have to be kept on […] If you're trying to go back to sleep [*groaning sound*].

A fellow focus group participant who had recently moved from the same institution also referred to her sleep being disturbed, this time by noise:

I wouldn't be able to sleep the way I should have been. All the noise would keep me awake. I would wake up in the middle of the night […] and then I used to waken up thinking of creepy crawlies in the bed.

Participants also spoke about the interpersonal difficulties of sharing a large dwelling or living space with others who engaged in behaviour labelled as 'challenging'. This issue was raised both by those currently living in a congregated setting and those who had previous experience of congregated settings:

What I don't like in [*name of service*], there's very disrespectful residents here […]they're very, they're very disrespectful towards the nurses and staff […] when I see that going on I speaks up you know, and then I'm the worst in the world because I speak up, you know. There's nurses there that have been injured and everything by disruptive residents in [*name of service*].

Overcrowding was another strong theme. People with intellectual disabilities supported in the community made references to *'getting in each other's way', 'too many people'* and being *'squashed in'*. Large groups of people were associated with noise:

I wouldn't like a big crowd now. Facilitator: you personally wouldn't like it? No Facilitator: ok, and can you tell me why you wouldn't like it? It would be kind of noisy. You wouldn't be able to talk.

A feeling of being overwhelmed was described by one participant:

I think it's not great because people have so many people coming to you. And you say no, that you've had enough.

On balance, the vast majority of participants' discussion on congregated settings was negative and emotionally charged. The only positive commentary regarding the supported provided in these settings was generated by people who currently lived there and referred largely to aspects of physical care.

Clustered living arrangements

Participants were asked about clustered settings as a distinct type of congregated setting, whether located in a campus setting or in the community. A descriptor from one focus group was:

> People live in houses where their neighbours also are using the service or have a disability.

Some of the individuals living in clustered settings in the community did not identify their situation as clustered. This was most apparent for a number of individuals who identified their residential living arrangement as 'independent living' on the basis that they had no night staff. Some of these properties were annexes adjacent to other larger properties owned and managed by the same agency. Others were properties located on campus.

It may be that people with intellectual disabilities were taking their cue from the terminology employed by staff. The comment below by one staff supporter attending a focus group lends support to this suggestion:

> It's called independent living. They are probably living in a cluster, because the houses are stuck together.

The interchangeable use of terminology may reflect the definitional issues which arose between clustered living arrangements and dispersed living options on the survey (see Section 4.1).

While the issue may seem somewhat academic, it may create difficulties in the future should individuals who expect to live in houses close to other agency properties find themselves instead in more isolated environments. For the purposes of the present study, the findings are framed from the perspective of the people with disabilities that participated. Their commentary on the merits of living in close proximity to others is noted in this section, while commentary relating to moving to living arrangement with reduced levels of supports will be presented in the section on independent living.

Proximity to friends was a strong theme throughout participants' discussions of clustered settings. Proximity brought opportunities to engage in shared social activities either in the local community, or in each other's houses.

> See I live in [*name of community cluster*]. Bridie is my next door neighbour and it's very good because I'm at the very end she's, in the middle and it's because we're the next door neighbours […] you can go to the shopping centre, and you can go to the café for cups of tea and coffee or cake or for a biscuit or for an apple tart and that. […] And we go to our house or whatever, or to the staff in the hostel.

The dialogue below illustrates how positive a group of people living on campus were about the prospect of moving to a cluster of housing in the community:

> But Patricia is going to share with me.

> Facilitator: You're going to share a house. OK. How do you feel about that?

> And Christine is the next door neighbour.

Facilitator: OK. This is getting really interesting [*laughter from group*] you're all going to be living close to each other?

Christine's next door to us. **Facilitator: Next door?** Yeah

OK Christine is number 1 and we're number 2.

It's only a wall dividing us […] Martin, Patricia, myself and Christine in the other house next door, wouldn't that be good?

As well as the social benefits accruing to living close to others, there was also a perceived security to this proximity if individuals needed assistance.

Well I have neighbours next door to me and if we're in trouble we can always go across and get them and they'll sort me out.

Drawbacks to clustered living included a sense of being overcrowded and inadequate staff support for community inclusion activities.

They can be on top of you, in and out all the time.

Like I go with my friends and I like I goes out with so many of them in the one week like. The boys go out one week and the girls go out – see there is only 10 people and there's only one house mother like, and I feel that she should have a staff with her, like, on a Wednesday, for people to go out.

Notwithstanding these drawbacks, clustered living arrangements were strongly endorsed by participants. The close proximity of others afforded opportunities for social engagement and security. The definitional issues which arise with this model largely equate to community clusters and independent living; some of the situations could be defined as straddling both options where people are afforded more autonomy in their supports, albeit while living in close proximity to other staffed housing. The commentary from one staff supporter suggests that both staff and people with disabilities use some of these terms interchangeably.

Community group homes

For many participants community group homes were synonymous with community living in general. The blurring of this particular model with the broader concept of living in the community is included in the presentation of findings below.

The general tenor of discussion was overwhelmingly positive, and this viewpoint was shared across those with different experiences of residential services. Those who now lived in community group homes had no wish to return to segregated settings:

Sorry, just to go back a step, when I was younger, I lived in a big place, as part of schooling. I wouldn't – today I wouldn't go back to it. If I got the chance in the morning I'd tell them where to go. Emm I wouldn't go back. If anything, I would go a step further.

Others on the cusp of moving from congregated settings perceived themselves to be entering a new and more fulfilling phase of life.

I'm glad to go out to the community where we can start off a fresh life for ourselves out in the community.

Those supported in more independent arrangements thought community group homes provided a good opportunity to hone one's living skills;

> Group home, you'd say it's good for people starting out, it's essential, that, it's good training for people, that they get their skills of keeping a house, the cooking, shopping and things or whatever, that… **Facilitator: So it's getting skills, yeah?** They have the support of somebody with them who will help them do all their work.

Those who had reverted to campus-based accommodation, largely due to insufficient supports to meet their needs in the community, expressed a wish to return:

> There's five of us in a house living in the chalets. It's grand. I'd rather live outside.

Three distinct benefits of community group homes were identified; a sense of personal freedom, more personalised staff support, and increased participation in community activities.

> You can do anything yourself. I remember years ago we used to have to go to bed early at nine o'clock and get up early in the morning. Where we're living now we can go to bed any time we like.

One participant who was soon to move from an institution to a community house was very clear on how she would like to exercise her new-found personal freedom:

> I get up early and do the breakfast and things and clean the house and do a bit of washing and things like that you know. And I'd have everything ready. I'd have everything ready for when we'd be after our breakfast and everything in the house clean and everything before we get any visitors you know. And we'd be ready for the visitors and get in a couple of things for them you know, and make them welcome to our new home, you know, things like that I would yeah […]I love cleaning and tidying you know. I'm a bit exact about things. [**Facilitator: and would you do that, would you get any help to do that, or would you handle that yourself?**] Myself.

Staff support was an important theme for people with intellectual disabilities generally. Specifically in relation to community group homes, staff support was perceived as less rushed and more personalised than in congregated settings:

> If you have ten people to look after, we'll say, it would be very hard to look after ten people in one go. That's why it's good for us clients to live out in houses. That the staff themselves are not in a hurry to look after someone else and you in a hurry to be looking after him. […] Staff are not rushing. They're taking their time.

Living in a community group home was also perceived to present more opportunities to engage in social and leisure pursuits.

> You go to town. You get to go to the cinema. You go swimming

> The shops are just up the road from myself and June, and the chemist.

Even those who had yet to experience community living felt that their intended move would provide extensive opportunities to use local facilities. The dialogue below illustrates the aspirations of those who were shortly to move to the community:

> Well I could make more new friends out in the community. I could go to down the town there. [**Facilitator: Go with who, sorry?**] Go with [*name of mainstream club*]. [*Name of club*] is a women's group you go down to, you know.

A group of participants living on a campus cluster discussed the challenges they experienced trying to meet each other socially.   They felt that community group homes provided more opportunities to meet friends.

> I love to do it. [*move to the community*] Because you can meet more people. OK […] And more freedom. Then you can go anywhere you want to go and meet your friends for, like if you want to meet Collette or Joan or anyone, I can't do that. And I love to meet Joan for half an hour or Collette for half an hour and I can't do that either you see.

Notwithstanding the high level of praise for community group homes, there were some undesirable characteristics which mostly centred on personal privacy.

> Someone came into my room and went through my stuff [Facilitator: ok, well that's a problem, isn't it?] Yeah [Facilitator; Thank you. And how did you feel about that?] Bad.

The vast majority of discussion was however in favour of community group homes as living arrangements which afforded opportunities for personal freedom, good staff support, and community engagement.

Independent living

Of all the residential options reviewed, this was the option where definitions varied the most. Those in smaller community-based organisations had heard the term previously; it was less well known in the HSE and larger agencies. After hearing the facilitator describe independent living, one participant commented:

> Independent living? Never heard that word. It's a good thing but I've never heard of it.

Although the notion of having one's own home is an important characteristic of independent living, just one participant in the focus groups spoke about accessing mainstream housing:

> I was put down for council house and then emm over in [*sheltered housing*] there was units there for people to live on their own you know. And then, I wouldn't like a unit over in [*sheltered housing*] because I'd sooner have a two storey house on my own or a bungalow on me own with two staff working with me.

Participants were more familiar with the concept of independent living equating with support as and when needed. On woman described this situation as 'excellent' adding,

> The reason why it's good about it is because I have a support worker coming in two days of the week. I've one woman. I've Deirdre coming in Monday now, into me, and she helps me with the cooking and that. And then Linda then, she comes in on Tuesdays and Thursdays and we go out for meals maybe, now and again, and we do a bit of shopping and that kind of stuff.

This participant's friend, also attending the focus group, commented on the personal gain he noted in this woman since she had moved to an independent living arrangement.

> I know [*woman*] since she's moved into her present living situation, she has improved 100% [*woman's name*] has come on a lot, in a very long time.

As well as receiving support as and when needed, increased personalisation of supports was identified as an advantage to independent living:

> I'm living on me own at night and then they're coming in part time, giving tablets and then going again on their own, going home for a half an hour and coming back into me again, bringing me to [*name of city*], [*name of town*], around the place, wherever I want to go.

Increased freedom to engage in community activities was associated by some participants with this model of support:

> I think there is one of them houses in [*location*] where Brian and Dermot live, and Fiona, independent living […] Yeah, they're in community living. They have a job and that you know. When you get outside the hostel, you can be more independent, like going on their own. I've thought of that.

A number of participants supported in large organisations equated independent living with living alone. Concerns were expressed about how individuals might cope on their own.

> I wouldn't like living on my own at all, because I would get lonesome. I'd rather not move away from the hostel. I'd get in a lot of trouble. I like living in the community. Probably six living in a house.

> I'd like to go out to the community but I'm too nervous to live alone and my Mammy won't allow it, because I'm very nervous.

Independent living was a new concept for some participants; those in smaller agencies were more likely to be familiar with this type of support. Independence of housing did not emerge as a distinct characteristic, rather more personalised and responsive support was highly prized. Few participants however were keen on the prospect of living alone.

Summary

The commentary from participants with intellectual disability suggests that most participants favoured living in the community. Congregated settings were largely dismissed as rigid, unpleasant and overcrowded places. Those currently living in congregated settings found some merit in the support they received, but this was largely in the context of being recipients of care. For others, these settings stirred up disturbing recollections. Clustered arrangements were more favourably viewed. Living in close proximity to neighbours afforded a combination of increased social opportunities in the community and support nearby should problems arise. Community group homes were similarly endorsed, albeit they were discussed synonymously with the concept of community living. Participants from a wide variety of experiences favoured this type of living arrangement as being personalised and community focused. A minority felt privacy was not respected in community group homes. Independent living was variously defined, some aligning more closely to clustered living given the close proximity to other agency properties. For those who experienced this model, a minority in small agencies, support as and when needed was highly valued. Some participants equated this model with living alone, a situation few welcomed.

5.3 PEOPLE WITH INTELLECTUAL DISABILITY'S PERSPECTIVE OF FACILITATORS AND BARRIERS TO COMMUNITY LIVING

Facilitators and barriers to community living were generated from the full narrative content of the five focus groups, as opposed to specific questions put to participants. For people with intellectual disability the primary theme and strongest overall facilitator of both moving to the community and remaining in the community while enjoying a good quality of life was staff support. Other less influential themes included other relationships and community amenities.

While the availability of staff support was universally valued, the manner in which that support was provided varied by participants' individual situations. People identifying with the independent living model of support sought assistance with practical tasks and with social activities, but prioritised the fact that support should be provided as needed. Control over when and how support was provided was very important to this group:

> Yes – simple. Someone you can call on if you need only. If you're already out and you need a support worker, they're there to call on, as you require them.

People moving to independent living aspired to the notion that support would be constant at the early stages of moving, but would become more flexible with time.

> I think when we go into our new home that the staff would be there for us for a certain amount of time.

The concept of support as needed was also valued by individuals in other living arrangements; in this instance a person living in a community group home:

> I've often said to someone – if I want help, I'll ask for it. Which is a good thing as well. That you're not looking for this, that, 24-7. Every five or ten minutes. Once you know what you're doing and where the stuff is to go, well, that's it. They're [staff] happy with that.

A number of participants indicated that they would be anxious without staff at night, which for many was synonymous with independent living. Others felt they could rise to the challenge:

> It would be hard I suppose but I'd get used to it.

People in independent living typically sought support to complete practical tasks included paying bills, managing money, taking out the bins and general housekeeping. These practical tasks were also prioritised by people living in community group homes, while those living in community clusters called for more support to socialise.

> If we did this outside could we get staff to take us somewhere like, to meet people, to have a cup of coffee or something like that?

Lack of support to meet specific needs was identified by participants as a barrier to community living. A number of participants described how their own changing needs could no longer be supported in the community; specifically age-related issues such as breaking a hip, health issues including epilepsy, and an escalation in behaviours that challenge.

> Yeah. I'm three years there now. I live in [*campus cluster*] and I had to come in from the community because I had a fall and broke bones and I'm three years down in the chalets now.

> The burden was on me, like. I got seizures and stuff then but I had to go into a hostel then in the end. It was for my own protection […] I had to change my arrangements then, when I got seizures then, I couldn't be covered then.

The question of why individuals with these higher needs are being removed from the community needs to be addressed as a matter of urgency. The imminent closure of congregated settings requires commissioners to consider a lifespan approach that ensures individuals with differing needs may all receive sufficient supports to live within the community.

Support from family was also mentioned, albeit less often than agency support, as an important facilitator to community living. Many participants spoke of regular and supportive contact with family.

My sister does be in and out to me. Anything I want they'll do for me. **Facilitator: so you get a bit of support from your sister?** I do yeah […] My sisters are very good to me, in and out […] she comes down on Friday night to take me out for a walk and all that and to help me out. Getting plenty of support…

Other participants described how families created barriers to community living by discouraging changes to living arrangements. Examples were given of resistance to people moving to the community, or to people trialling reductions in staff support. It seems that depending on individual circumstances, families may either 'make or break' a move to the community.

Friendships were also cited as an important consideration influencing a person's living arrangement. For some, these friendships referred to long-standing friendships which had been displaced when the person entered residential services. Re-establishing these old friendships was an aspiration if individuals could move back to their place of origin. For others, the friendships referred to those they had met within residential services. Some feared a change in living arrangement would disrupt these friendships. Friendships could therefore either work as a facilitator or a barrier to community living.

I live with Marian now and we're great pals and we get on. I think for other people in the house like, and I get on with Clare and all my friends, and I'm happy living in [*place*] with Clare and the rest of my friends and I'm happy where I am in [*place*] and I'm happy not to change.

Neighbours were generally thought to facilitate community living. Most people described warm and reciprocal relationships with their neighbours.

[…]she called to me and yesterday morning when I was walking down by her door, she opened her door and she said I called to you last night and I said that I was gone out and she thought then that I was sitting up the back.

A number of participants noted that their neighbours were 'quiet', a trait which they valued. The only negative commentary that arose with regard to neighbours was generated by participants who did not live out in the community. This group recommended that *'it would be better not to get to know your neighbours'* for fear that they *'mightn't want you'*.

This commentary reflects other concerns from some individuals about the broader community, again not relating to people specifically known to the participants.

Because there's lots of queer lots around in the streets, a lot of winos now, they say and there's lots of emm fellas now, they'd rape you and doing something to you, which is not right, anyway.

In both cases these negative comments about neighbours and the broader community were generated by people living in clustered arrangements in larger agencies. The views may reflect a fear of the unknown as those participants who had neighbours were positive about these relationships. Greater exposure to the community is needed to quell these concerns.

Most of the commentary from people with intellectual disability regarding facilitators and barriers to community living centred on support gained from various stakeholders including staff, family, friends, neighbours and the larger community. Less cited were more practical aspects of community living, of which proximity to amenities dominated. Some participants commented that their isolated locations meant they were reliant on staff to drive them to places, or to use taxis. Public transport was not mentioned. Taxis were deemed too expensive, resulting in participants at one focus group opting to use the agency bus to take them to a day centre. The lack of alternative transport options impinged

on some participants' independence. Living nearby amenities provided more opportunities to exercise independence.

I like to walk to work on time you know. I like to do that.

Summary

The support provided by key stakeholders is a key determinant of community living for many participants. Staff support as required was an important facilitator for people in independent living. Support with practical tasks was important for people supported in independent living and community group homes, while support to socialise was prioritised for people living in cluster arrangements. Families were a pivotal influence in decisions to change a person's model of support; it seemed their endorsement could make or break these decisions. Friendships too were an important consideration; some individuals wished to reconnect with old friends from the community, others feared losing friends they met through shared residential services. Within the broader community relationships with neighbours were a facilitative factor; however those with limited experience of community living were fearful of neighbours and the broader community.

Most of these relationships acted as both facilitators and barriers to community living. In contrast, the lack of sufficient and appropriate supports within the community for people with specific health and age-related needs was a distinct barrier. This is an issue which urgently needs to be addressed; presently a revolving door scenario exists where individuals moving to the community revert in time to more congregated support options. A lifespan approach is needed giving due consideration to changing needs associated with ageing. Poor location was also cited as a barrier to community living leading to individuals relying on agency supports and losing important opportunities to exercise independence.

5.4 PEOPLE WITH INTELLECTUAL DISABILITY: TRENDS BY AGENCY TYPE AND REGION

Trends by agency type are apparent in the discourse from people with intellectual disability. People supported in congregated settings were more positive about the support received in these settings than others who had moved to more personalised services. People living in clustered arrangements, whether in the community or on campuses, were more likely to discuss the merits of physical proximity to other people using the service. Much of the discussion of independent living was generated by those supported in small NGOs.

These distinct groupings are linked to distinct organisational types. People living in a congregated setting were supported by HSE; people living in campus clusters and community clusters were more likely, but not exclusively, supported by large agencies. People in independent living were most likely supported by smaller, community-based agencies. In combination, these findings indicate that the preferences and opinions of the people supported in these different living arrangements are largely shaped by their personal experiences.

Differences in the narrative of people located in the two case study regions were more nuanced. The main difference was their perception of clustered living arrangements. Participants living in Region 1, which has documented slower progress to community living, were more likely to cite advantages to living in close proximity to neighbours who are also supported by the same agency. Proximity was a significantly lesser theme for those living in Region 2. When these participants were asked if they

thought there were merits to living in close proximity; the general consensus was *'no, that wouldn't be good'.*

It could be argued that this regional difference again reflects the lived experience of participants given the dominance of cluster living arrangements in Region 1 (see Table 4.1). It may be that certain living arrangement models are preferred by specific agencies, reflecting the ethos and values of the agency. These preferences become the lived experience of those receiving the agency's service, which through familiarity becomes their own preference. More support is needed to empower people with intellectual disability to consider potential opportunities beyond the familiar.

Summary findings from Results: The Perspective of People with Intellectual Disability

• Many of the participants had experienced a number of different types of living arrangements throughout the lifespan; some had moved to the community from congregated settings, others had reverted to these settings when ageing needs could no longer be supported in the community. The issue of how equipped agencies are to support individuals live in the community across the full lifespan requires urgent attention.

• Most participants were satisfied with their current living arrangements with the exception of those living in congregated settings who were awaiting a move to the community

• Congregated settings (excluding clustered living arrangements) were generally perceived as rigid, unpleasant and overcrowded dwellings; those currently living in congregated settings expressed some satisfaction with these settings, largely within a caring context.

• Clustered living arrangements were more positively endorsed as they provided close proximity to friends and support in times of trouble – some called for more staff to support social activities.

• Community group homes were highly regarded by a wide variety of participants – albeit they were somewhat synonymous with the broader notion of community living. They were deemed to afford personal freedom, more personalised support and more opportunities to avail of community amenities, albeit some felt privacy was not respected.

• Independent living was well known by only those supported in small agencies – definitional issues arose where some independent living options may be also deemed community clusters. Support as and when needed was highly valued by proponents of this model.

• Support from stakeholders is a key facilitator of community living; from staff, family, friends, neighbours and the wider community.

• Inadequate support to meet emerging health and age-related needs was the key barrier to community living; a lifespan approach to community living is urgently required. Isolating locations were also a barrier.

• Differences by organisation type were apparent in the participants' commentary; people's preferences for particular living arrangements typically reflected their own personal experience of the types of places where they lived

• Differences by region were also apparent but more nuanced relating mostly to clustered living arrangements. These are more dominant in Region 1 and were more preferred by people living in this region

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• These differences suggest that specific residential models are preferred by specific agencies; these models become the lived experiences of those receiving services and in turn become their preferences

• People with disabilities need to be empowered to make informed choices about opportunities beyond their lived experience

6. Results: The Perspective of Family Members

Six focus groups were conducted with family members; three in each of the two case study regions. Within each region a separate family focus group was hosted for families using HSE services, those using the services of a large non-statutory provider and those supported by a small non-statutory provider respectively. Findings from these focus groups are presented in four sections below: the role of the family and engagement with stakeholders; perspectives on different types of living arrangements; facilitators and barriers to community living; and evidence of any differences in family opinion depending on which region and which type of living arrangement supported the person with intellectual disability.

6.1 LOCATING FAMILIES WITH THE SPECTRUM OF STAKEHOLDERS

The primary role of families engaging with services was advocating on behalf of their family member. Families were not passive observers of services, rather they actively engaged in lobbying for better services to meet need. Many spoke of the struggles they endured to obtain and maintain services, and the personal toll they paid for the ongoing stress associated with advocacy. They spoke of an invigilating role, conducting 'spot checks' where they arrived unannounced at services to glean an insight into how their family member was supported. Some felt these spot checks were an important motivator for staff to maintain standards. The recent cuts to service provision were a source of considerable concern heightening the need for families to advocate for services.

> But they're doing it [*cutting services*] to people who can't speak for themselves, a lot of them, you know what I mean. Sure we're their voices.

The response by agencies to family advocacy was mixed. Some families experienced a listening ear, others a sense their views were dismissed.

> I always feel that I'm an advocate and I'm always pushing [..] but at the same time there's always an open door being pushed. It's not defensive. It's not closed down.

> Those staff, they were just desperate. They've no understanding. And they think we're being awkward you know, if you raise issues and that. They think you're being awkward but [*individual began to cry*] but you know they don't want to hear it. You're the worst in the world if you say anything.

Many participants spoke of the potential benefit of peer-to-peer support among families, yet there was virtually no support by service agencies to facilitate family members to meet. Members from just one focus group reported having met previously, but this was purely in the context of a Christmas social event. What families wanted was the opportunity to meet to discuss issues of service provision. Many participants commented on the benefits of contributing to the *Moving Ahead* focus groups, and lingered long afterwards to talk about shared experiences and concerns.

Only a small minority of families described accessing professional advocacy services, typically peer support agencies such as Inclusion Ireland. Experiences of these agencies were largely positive, with information on policies and practices being particularly valued. Others felt particular agendas, notably community living, were prioritised by some advocacy organisations and were beyond criticism.

> There is huge - what do you call it - awareness of this whole move into the community and in actual fact I'd say for Mother to have voiced her concerns about not moving into the community, would be almost frowned upon there over the years.

The general tenor of discussion regarding advocacy was disappointing. From the perspective of personal advocacy, family members reported having to pressure services to maintain standards. Families sought the empathy of other families who shared their lived experience, but found little support to facilitate peer to peer interaction from service agencies. Families described feeling isolated from the more radical views of some professional advocacy services.

Relationship with direct support staff and management

Direct support staff were identified as the main interface between family and service providers. They were the most frequently mentioned stakeholder by family members indicating the pivotal nature of this relationship.

Generally, families provided mixed feedback regarding their relationship with direct care staff. For some, direct support staff were deemed to have become as close to the supported person, if not closer, than family.

> My brother can't speak. But his face would light up because he's obviously fond of one [*staff*] more so than the other. Whereas when I come in I don't think – the only thing he looks at me for is the bag that I'm carrying [*laughing*] as much as to say, what did you bring!

Other families expressed frustration and anger at what they perceived to be disrespectful and unprofessional conduct from direct support staff. One mother reported how a staff member was unhelpful in accommodating her son's toileting needs:

> Barry wears the [*brand*] nappies and on the Friday he was going into respite and she [*staff*] said 'I'm finding it very hard with the [*brand*] nappy on Barry'. I said, 'What?' I said, '[*Curse*], I've no problem, [*name of other staff member*] has no problem. Nobody has any problem.'

Professional and timely communication by direct support staff was highly valued. Communication was positively described for some, but situations arose for others who felt that communication was either lacking or disrespectful in tone. The quote below illustrates one mother's offence at a staff comment regarding the arrival of her daughter at the service.

> She said [..] 'Rachel, her pants were wet coming in on the bus this morning. I just thought that I'd point out to you that it can happen' [*gasping*] and I got in touch straight away with [*service manager*] and she had a fit over it.

Poor and untimely communication about proposed changes in residential supports was a specific point of contention for many families. Given the proposed reconfiguration of services will likely impact on many families, these communication difficulties will do little to quell their concerns.

> In the end she [*key worker*] decided she wasn't going and the other girl [*a support worker*]. The two of them were supposed to go, had done courses and everything, said they weren't going. Just out of the blue. Oh Mother of God. And we had consented for him to move out at this stage, and you know, that is a big blow, you know.

Communication from staff regarding independent living models in particular was a negative experience for many family members. These families reported feeling pressurised by agencies to support their relative to move to a more independent model of support. They also felt their concerns were dismissed. This quote from one mother provides an indication of how excluded many families feel within this process:

> She's [*daughter*] moving out whether I'm on board or not. That's her very words. She's actually moved out on two different days getting her used to the house without the family being told, or notified […]. I visit her every week. And there was not one mention and I accidently found out.

Agency management were stakeholders of lesser relevance to family members than direct support staff. This social distance was reflected in a reduced commentary about management. Engagement with management varied among participants, from very little contact through to membership of the Board of Management. Matching the feedback on direct support staff, families reported mixed experiences in their engagement with management. Examples were provided where dissatisfaction with direct support staff was reported to management who had successfully resolved the situation. In contrast, other families described feeling disrespected by management, largely related to the issue of changing levels of support.

Relationship with HSE and Policy Makers

In discussing HSE as a stakeholder, families typically referred to HSE within its remit as a commissioner of state services rather than as a provider of services. Within this context, the relationship between HSE and families could, at best, be described as poor. The focus of negative commentary was a distrust of the HSE's motivation in changing service delivery.

> I have a concern that the HSE would be anxious to close all the larger institutions and put people into that kind of setting that it mightn't be right for them […] But it would fit the plan of the HSE and you know, and I'm just sceptical about what they're up to, to be honest about it.

HSE policies for future service delivery were deemed to be based on finance rather than on the well-being of supported individuals. Families felt that HSE would, in time, become a commissioning body only and would begin to rely more heavily on services from private, for-profit providers. This prospect was universally unwelcomed by families.

> The HSE will outsource a house to a company and they will give them so much money per week to run that house and at the end of the day then, it's a business. And what happens then, it's not a caring profession then. It's a business.

Overall, there was a significant level of distrust and lack of confidence in the capacity and intention of HSE to continue providing adequate or improved supports.

Policy makers were similarly distrusted. Not one family reported being consulted during the preparation of the raft of recent disability policy in Ireland. Many were unfamiliar with specific policy documents but were aware at a broader level that policy advocated closing larger facilities and reducing supports for some individuals with low support needs. Both prospects were met with fear by many participants. Some expressed their anger and frustration.

> I would like to bring James Reilly, [*Minister for Health*] down here, Kathleen Lynch [*Junior Minister with remit for disability*] down here. Bring them down, take them around, whole facilities, bring them down for a full week […] See what's been done. See what is being taken away.

Many felt that policy makers were motivated more by financial considerations as opposed to any effort to raise the quality of service provision.

> Well I think the issue is not with the house being set. The issue is with the finance. Sometimes, you'd wonder is some of this financially driven [...] Well I mean to move them out, is it cheaper to have them out in the community, rather than to have them in the grounds?

These concerns about financial motives arose within the context of the significant financial cuts to service providers resulting in families being asked to co-fund aspects of care that previously were paid in full by providers.

> I think the last three months I had to get a commode. I had to get a full dresser for her bedroom, with side lockers as they were too small. They're [*agency*] asking family members for supports in these areas. Because of the money.

Summary

The role of family members within the system of service delivery was characterised by one of advocacy and vigilance to ensure standards were maintained. Relationship with agents of service delivery, direct support staff (the main interface with agencies), management, HSE and policy makers were positive for some, but for others could be described as unsatisfactory. HSE and policy makers in particular generated almost universal negative commentary. Dissatisfaction with communication from all stakeholders was a key theme underpinning much of this commentary. Trends towards more independent living options in particular were met with suspicion as they were perceived as exercises motivated by finance.

6.2 FAMILY PERSPECTIVES ON LIVING ARRANGEMENT OPTIONS

Congregated Settings

Family perspectives on congregated settings were mixed and highly dependent on the current living arrangements of their family member. All positive commentary regarding congregated settings was generated by those whose family members were currently supported in these settings. This reflects a similar pattern of commentary from people with intellectual disability where only those currently living in these settings cited positive elements of their care.

Three themes dominated; high standards of physical care, consistency of staff and place, and access to spacious grounds.

> The buildings may be oppressive looking which they are […] but when you go there, and you go there all the time, and you see the commitment and the staff and the members, the residents, you know that they're in the right place then.

Consistency, predictability and continuity were particularly valued by those whose family member had high support needs. These families spoke of their hopes that their family members could age in place in these settings, and were fearful that any change in living arrangement would have devastating consequences.

> I think if they shifted him [*participant's brother*] from a ward, I'd say he'd last not a year because I think he gets the, it's the atmosphere of the one room, they all live through each other, even though half them don't communicate and they don't talk.

Notwithstanding these positive aspects, the balance of commentary on congregated settings was negative and was dominated, albeit not exclusively, by families whose relatives lived in the community. Two themes were identified in this negative commentary; a general aversion to the concept of supporting large numbers of people in one setting, and a perception that individualised needs could not be adequately addressed within these environments.

> I don't think it's natural for people to spend their whole lives in a very large group of people and living completely different lives to you and me.

These participants suggested that the delivery of personalised supports was incompatible where services were supporting large numbers of people. Staff would simply not have the time to provide the level of one to one support that was possible in smaller, community-based houses. Also these family members argued that the level of activity, particularly in cases where settings were in segregated locations, could not compare with the opportunities afforded in the community.

> Yeah it's only when Mark moved out that, you know the way, obviously he's washed and he's fed and you know, he's clean and whatever, but with regard to stimulation, we felt you know, there's not as much of that you know, in congregated as opposed to when he's out.

Congregated settings divided family opinion. Current users of these services identified various perceived benefits. This contrasted with the opinion of those who currently used community-based services who identified both conceptual and practical difficulties.

Clustered living arrangements

Clustered living arrangements were discussed both in terms of clustering of properties on campuses and clustering of houses within the community. Campus settings tended to dominate the discussion.

Much of the commentary was positive relating to increased quality of life and improved physical environments when compared with institutional provision, increased opportunities for social engagement among neighbouring houses, and increased opportunities for staff support.

> It's in a chalet or a little small house and they'd be about six that are living there, six to eight probably, and it seems to be a great set up. She seems to be quite happy, you know. Much more so than when it was a big dormitory, you know. That's my feeling on that one anyway, you know.

Social opportunities for those living in close proximity in the community were thought to be enhanced as neighbours could rely on a large pool of friend to socialise with.

> There's kind of a double house where they came over from one to the other. They go out now to bingo, the ones in her house mightn't go and, but the ones in the [*other*] house then could be going. So they join up like that which is good. So she's the option of going with either house, which is supervised.

Staff could also rely on each other in contrast to staff working in dispersed community housing which, by definition, was thought to be more isolating.

> You've good help if you've two together and there's an emergency in one house, which can happen.

As observed in the commentary on congregated settings, much of the positive feedback on clustered housing was generated by those whose family member availed of this type of living arrangement. In contrast, negative commentary was provided by both these current users and by those living in dispersed housing. Two themes are reflected in these discussions; concerns regarding the ghettoisation of those supported in the community, and a perceived lack of homeliness to clustered settings based in the ground of service agencies.

> Yeah, I suppose that sense that you know, that's the disabled village or whatever, that they're a group apart.

Notwithstanding these criticisms, the general tenor of discussion indicated most families were positively disposed to clustered living arrangements.

Community Group Homes

The community group home was the model that synonymised community living for families; often their discussion broadened to the larger debate regarding community living, irrespective of whether people were supported in community group homes, community-based clusters or more individualised supports.

Positive commentary was classified to three themes; favourable comparisons with campus-based living, more personalised staff support, and greater opportunities to socialise.

> It's probably taken us three years to realise right how good it was. The transition was huge, and then the changing of clients and the changing of staff, but now you just go over and it's amazing, absolutely amazing.

Families remarked that community group homes were an inviting place for family visits, noting that they were never made unwelcome in larger settings, but that they were 'more inclined' to visit community housing.

Greater social opportunities were perceived to arise in community living, when compared not only with more congregated type living arrangements, but also with life in the family home.

> He goes to parties. He you know, lots of places that he would never have went when he was home. And even the whole thing of meeting people. It's been great for him.

Families also expressed concerns about community living, specifically its appropriateness for people with high support needs, the potential for isolation, and concerns about staffing.

Isolation was driven by two issues; geographical and social. Some houses were in remote locations and concerns were expressed that without sufficient transport both family members and staff may become extremely isolated.

> From a social point of view they're [*staff*] just going in and all the people they trained with, they don't see them. They're just in one house with 4 people.

Other families worried that their relative may become isolated and lonely as there was little evidence of efforts to facilitate social engagement.

> Even though they may say she's living in the community, because the house is in a row of houses, but it's strictly isolated really from everybody else. And nobody ever drops in, nobody has sort of any friendly relations.

Families expressed concerns about a perceived lack of staff oversight. They called for an increase in the frequency of routine inspections which they felt should be conducted by an independent body. Several examples were provided of inattention to personal care which was of great concern to families.

> I feel that my one is just put into one of these relax chairs to be honest all day. Julie loves to move around as long as she […] but I think it's getting too much trouble now for them to walk behind her.

Examples were also given of families not being listened to with respect to the preferences of their relatives.

> Well she was destroyed. She was all marks from biting and scratching and they never took her out [*person was attending a community event*]. And I have asked them - for God's sake. And it was 'oh no problem, she'll be taken out as soon as she gets agitated or she shows any distress.' They kept her an hour and a half in there. And she was so distressed.

Community group homes were generally perceived as providing more personalised supports with enhanced opportunities when compared with congregated and clustered housing arrangements. Families did express concerns, not regarding the concept of community living per se, but rather regarding badly implemented support including isolating locations and inadequate staff support. The dispersed nature of community group homes was associated with less staff accountability, a position which jarred with families' needs for reassurance regarding the well-being of their family member.

Independent living

Families were not entirely confident about what exactly independent living comprised, but were very clear that they perceived this model as synonymous with a reduction in staff support.

> I have a vision that you will be in a normal house as you're calling it, in a house in a town, but that the nursing staff would call, maybe check every day, and that maybe that an assistant would go in maybe once or twice a week just to make sure everything is cleaned up.

Some families indicated that this type of living option was, in theory, a good model of support albeit no specific positive aspects were generated. This contrasts with the views of participants with intellectual disability, some of whom expressed a preference for greater control over when and how their supports were delivered.

Not one of the family members who participated in the focus groups endorsed this model of residential support for their own relative. At issue was the perception that independent living was only appropriate for a minority of people with intellectual disabilities.

> I don't think there'd be many that would be suited to independent living. We'd all like if they were suited to it.

Four themes captured the families' dialogue on independent living options; only for individuals with low support needs, 'not for my family member', perceived pressure from agencies to move to this model, and concerns regarding its sustainability.

My son, no way could he ever be independently living. He's very disturbed. He can be very disturbed and he's fully dependent on the staff.

Notably, in two agencies where independent living was being specifically promoted (one in each region) the general response from families was feeling pressurised and fearful of a reduction in support. For those who had been approached by agencies to discuss the possibility of their family member moving to independently living, the communication was poor with some receiving discouraging messages from staff.

One of the house parents said to me that if she moves out, she could not take part in those facilities [*community outings*] with the ones in the group home.

A major concern for families was a lack of confidence in the sustainability of this model, and associated with this, a fear of the transfer of the burden of support and responsibility back to the family members. Families were fearful that their caring responsibilities would increase as they themselves aged, a situation they deemed unsustainable. The communication style of one agency was spectacularly misaligned with the wishes of this family member for her retirement:

The words that were used was 'It's like giving your adult back to you.' And like, I'm not sure at this stage if I want my adult back to me. How would I cope with Elizabeth now again? Like [*curse*] I couldn't cope with her when I was 50. I can't cope with her now, you know?

The families also queried whether the supports provided to some individuals in independent living were sufficient:

There are a few in [*name of town*] in independent living and I wouldn't, you know as well, I wouldn't be satisfied with…. I don't think some of them are supervised at all.

Independent living was the least favourable living arrangement for family members. This contrasts with the views of participants with intellectual disability where congregated settings received the bulk of negative commentary.

Many families perceived independent living as a model of support for those with low support needs, and none endorsed it for their own family member. The main concerns were the potential transfer of support back to families, and a lack of confidence in the long-term sustainability and resourcing of this model of support.

Summary

Taken in combination, the perspectives of families to the four living arrangement options suggest that their preferences are largely influenced by their own lived experiences; for example, only those whose family member was supported in a congregated setting identified positive characteristics of this model; no participants deemed independent living a suitable option for their own relative, and no positive aspects to this model were explicitly stated. It would seem that families are currently working through a lens of personal experience and require more support to consider other viewpoints. The influence of lived experience was also a feature of the commentary from people with intellectual disability.

The finding may be linked to the observation that families have few, if any, opportunities for peer-to-peer support. It may be that hearing the experiences of others may result in some flexibility about their current perspective. The manner in which some options, notably independent living, were presented

to families may only serve to entrench their views. Feelings of being pressurised into changing supports and fear regarding inadequate staff oversight in the community are unlikely to address their concerns. It is perhaps unsurprising therefore that families gravitated towards the concept of cluster arrangements which incorporate both traditional elements of services, such as high levels of staff supervision, married with increased opportunities for social activity in the community, albeit likely in large groups under supervision.

6.3 FAMILY PERSPECTIVE OF FACILITATORS AND BARRIERS TO COMMUNITY LIVING

Families identified several factors they felt would assist people with disabilities make an effective transition to the community and moreover, to maintain a good quality of life in their new community residence. These factors included continuity, resources and relationships.

Families prioritised the need for timely information regarding the staffing of new residences. Where new staff were to be employed, effective transfer of information between old and new staff was crucial to ensure continuity of support. Many family members related to one participate who spoke of her frustration at having to repeatedly relate the same information about her brother to a series of staff due to high staff turnover.

> It's such a big thing for families when somebody is moving out, you know, that whatever information is given, you know, it is captured and documented and if somebody [*staff*] leaves or moves off, you know that there is that…

The provision of appropriate resources, whether staffing or environmental, emerged as a precondition of family confidence in the provider agency. Concerns were expressed that inadequate numbers of staff were being allocated to community residences. Levels of night staff, in particular, fell below a number of families' expectations.

> The only thing now at night time is when he moved to the house right, you had support staff and you had a nurse all day, well you still have that. And at night you had a nurse and a support staff, and you really need two people […] it's very hard on the one person [*staff*] there at night.

The property itself, and specifically its location, was also identified by families as playing a key role in maintaining a successful community-based living arrangement. For a number of family members the scale of the property and its adjoining land was a consideration, most especially for individuals who may be moving from large institutional settings located in expansive grounds. Families felt these individuals would not cope well moving to a typical size property located in a busy housing estate.

> It depends on where they buy the house. I mean if they buy it here in a group of other houses, I don't think it's a great idea. Like Linda's house is out in a field, you know. The houses aren't that near. You wouldn't, you know... and they have good big grounds with it. And they're able to keep a dog and that.

Other family members identified the source of concern regarding housing estates; a fear that individuals with disabilities would become the target of abuse, particularly from adolescents.

> And in large housing estates, I mean I've had experience of this myself - my previous work. People with disability in a house in the community who you know, young teenagers throwing stones at night and bullying.

These findings reflect a reluctance by some families to locate people with disabilities within local communities, their visibility alone being a source of potential abuse. For some, more secluded

locations would avoid any potential for disharmony between individuals with disabilities and their broader community.

Community living was also facilitated by positive relationships between individuals with disability sharing the property. Families advocated that consideration be given towards identifying potential housemates who had similar levels of ability, and a 'good match of personalities'. Most families also agreed with the HSE recommendation that four individuals was an appropriate number to share a community property.

> It's fine if it's the right mix. *To live together.* If it's possible to get four people that are going to gel, and you know are going to.

In summary, continuity of support and good information transfer were perceived as key facilitators of community living by family members. Also, adequate staffing, consideration of the location of the property, attention to the compatibility of individuals, and supporting no more than four persons in one property were all deemed by family members to maximise good quality outcomes for those transitioning to the community.

Four barriers to successful community living were identified by families; support needs, confidence in the sustainability of some models, the response of receiving community and the impact on the individual.

The strongest barrier identified by families to moving individuals from congregated to community-based settings was the level of support required by individuals:

> There are still a hardcore of seriously disabled people that will have to be kept in a really safe and caring long term setting that they may never leave. And it [*name of congregated setting*] would be the best for those particularly, that particular category.

Having high support needs was deemed by families as the biggest barrier to community living. The age of many of people currently in congregated settings was acknowledged as a related barrier. Participants spoke of individuals who had lived a life within institutions, proposing that their moment for a new life the community had passed. A selection of quotes from families below poignantly illustrates how they felt these opportunities had slipped away.

> She would have been so active, she could speak. She knew what she wanted. And [*independent living*] would have been perfect for her.

> She's 42 years there now [*in campus setting*]. I mean she's totally institutionalised.

> Going back in the 50s and 60s there's no doubt […] but there were people in there [*congregated setting*] that would have excelled out in the community […] if those people had got a chance to live in the community like they would have absolutely excelled out there. But they never got the chance.

Some family members queried the wisdom of moving people from middle age as they predicted these individuals would be required to move back to a generic congregated setting, for example, a nursing home, as they became older.

> We're all going to get old and crocky, bedridden and everything. What happens then, when they reach a stage or an age that their home - their group home - is not suitable?

Both family members and participants with intellectual disability identified support needs as the key barrier to community living, but there are subtle differences in their perceptions. Participants with intellectual disability spoke of the prospect of changing support needs resulting in re-

institutionalisation for people living in the community. Families in contrast, were more likely to perceive current high support needs as a barrier to ever moving to community living. Irrespective of their differences, both groups of participants perceive level of support need as the major barrier to community living.

Another key barrier for families was a lack of confidence in the sustainability of some community models. Specifically, families had concerns about staffing levels and were generally unwilling to relinquish the supports currently available to their relative in order to access a more individualised, but unchartered arrangements where support was reduced. Families were concerned about the introduction of more fragmented services.

> My friend - her daughter is in a different organisation - and there is very much a fluid situation about 'We rent a house here, and we'll fully staff it, but you might change from that house now because we're fitting clients in.' There's not that security – that's the downside I see.

Further to the sense of loss of a secure, permanent arrangement, some family members expressed concerns regarding how agencies would cope with placement breakdown in the absence of having a congregated setting that individuals could avail of over a limited period. Families from one agency, which was in the process of winding down a congregated setting, expressed favourable views about retaining a building on the campus as a 'fall back building'. One family member described this as a:

> purpose built building […] where you could bring those people and maybe even they could stay a while until things settle and maybe come back [to the community group home].

The issue of abuse within the receiving community alluded to above, is presented again within the context of a barrier to community living. Much of this commentary was from participants who had moved to community services some time ago and reflected on historical opposition by local neighbourhoods to the establishment of community group homes in the area.

> That house wasn't really approved years ago. They [*neighbours*] didn't want a house. Remember that […] But these didn't actually move because there was an objection to them, so they didn't actually go to live there.

When asked whether they perceived this community resistance to still exist, one family member answered, *'I don't know, that's what I'm wondering.'*

This overt type of community resistance was largely thought a thing of the past, however the broader issue of stigma and disability awareness was important and mentioned in many focus groups. Some family members felt stigma existed for their relatives and gave more subtle accounts of unfair treatment or discrimination they had experienced. Families were particularly concerned about the response to behaviours that may be deemed inappropriate by the wider community.

> I worry about society as well. […] if you have somebody who has kind of, wants to go out and start shouting around the place, which happens, and if you have somebody who might want to in the day go out and take off all their clothes, and it happens…

Apart from stigma and lack of disability awareness, a reduction in community capacity in general, not specific to people with intellectual disabilities, was deemed a barrier to neighbourly involvement:

> The day television came in everybody was looking at some programme and there's no welcome for you.

Families also identified their concerns regarding the impact of transitioning for their relative. They worried if people would miss their friends from congregated settings, and whether they could 'adapt'

successfully to the community. This concern echoes that of people with disabilities who noted that potential loss of friendships were a barrier to community living.

Families found it difficult to dwell on the emotional turmoil such a move may have for their relative. For example, one mother related how her son had moved from a congregated setting to a community group home, but returned to the campus to see a health professional:

> And [*name of staff*] told me when he walked in, he walked straight up and into his bedroom. But his bed wasn't there, you know. I was like oh God, I wish you hadn't told me that you know. You know, that kind of oh stop it, you know!

Summary

Families prioritised the need for good continuity of information and supports for individuals moving to the community. Consideration was required for appropriate housing, staffing levels and selection of housemates. The main barrier families identified to living in the community was the individual's level of support needs; families proposed that people with high support needs and those who were ageing may not be suitable candidates. Moreover, families questioned the wisdom of closing congregated settings only to find some individuals will require this type of support from nursing homes and other care facilities as they age. The response of receiving community may also become a barrier, albeit some felt this issue may be historical; hostility in previous years to people with disabilities living in the community was perceived to have reduced. Irrespective, local communities were thought less likely to have the social capital which was once available. Finally, families were concerned about the emotional turmoil such a major life transition may have on their family member. The issue was difficult for families who felt somewhat powerless to provide protection.

6.4 FAMILY TRENDS BY AGENCY TYPE AND REGION

A clear trend emerged in the families' commentary indicating that their views and preferences are largely shaped by their personal experience. The agency from which families received services, and specifically, the type of living arrangement offered by the agency to support their family member, was a strong predictor of their perspective on community living. The clearest example of this trend was that all positive commentary about congregated settings was generated by participants whose family member currently lived in these settings. This trend suggests that families need more support to envisage a life for their family member in an alternative living arrangement.

At regional level, differences in perspectives were also apparent. Families in Region 2, the region progressing more rapidly to community living, were more likely to report feeling pressurised from agencies to consider a change in living arrangements. This commentary was particularly evident from families supported by the HSE and larger organisation in Region 2. These families were more likely to report feeling pressurised to consider dispersed community living options, and independent living in particular.

Notwithstanding these trends, much of concerns expressed by families were similar across regions and across organisational types. These concerns may be deemed as universal.

Summary findings from Results: The Perspective of Family Members

• The main role identified by families in their engagement with disability agencies was that of acting as an advocate for their family member

• Direct support staff were the main interface between families and agencies – these relationships were positive for some families, but poor for others.

• Relationships beyond agency level, with HSE and policy makers, were typically strained; families reported poor communication and distrust regarding the motivation for changing service delivery.

• Families' preferences for different types of living arrangements largely reflected the type of support their relative currently received.

• Families mostly agreed with the principles of independent living, but none felt this type of living arrangement was a suitable option for their relative.

• The manner in which organisations presented the option of more independent living options was perceived poorly by a number of families who felt pressurised and disrespected in these discussions.

• Families gravitated towards cluster living arrangements which they felt married opportunities for social inclusion and high levels of staff supervision.

• Facilitators for community living, in the opinion of families, included continuity of information and support, appropriate housing and staffing levels, and consideration of the group dynamic for those sharing a home.

• The main barrier to community living, in the opinion of families, focused largely on the person's support needs; those with high support needs were not deemed suitable candidates.

• Other barriers to community living included potential negative response from receiving communities, a lack of appropriate services for individuals as they age, and the personal impact of such a major life transition on the supported individuals.

• Trends in responses from families were apparent, by agency type and by region. A clear pattern emerged where family preferences were allied to the type of support their relative received; this was most evident for those with a relative supported in a congregated setting as they were the only group to identify the merits of this type of support. Regional differences were more subtle, but did reveal that families in the more progressive region were more likely to comment on feeling pressurised to change the living arrangement option of their relative.

7. Results: The Perspective of Support & Clinical Staff

Eleven focus groups were conducted with direct support and clinical staff; ten of these were conducted solely with direct support staff, just one with clinicians. The majority of findings therefore represent direct support staff. Four focus groups were conducted in small organisations (1 in Region 1; 3 in Region 2); three focus groups were conducted in large organisations (1 in Region 1; 2 in Region 2, of which one was with clinicians); four in HSE services (2 in each region; one with staff working in institutions, one with staff working in the community).

Further focus groups with clinicians were intended and facilitated but were poorly attended. Feedback from agencies indicated that most clinicians are not centrally located and scheduling a time when they could convene together in one location was problematic. The views of the sole clinical focus group were found to align most closely with those of direct care staff and are therefore included in this section.

Findings from all eleven focus groups are presented in four sections below: organisational culture within agencies; perspectives on different types of living arrangements; facilitators and barriers to community living; and evidence of any differences in staff opinion depending on the region and type of organisation staff represent.

7.1 ORGANISATIONAL CULTURE

The influence of organisational culture on deinstitutionalisation is reviewed in the companion *Moving Ahead* report *'Living Arrangement Options for People with Intellectual Disability: A Scoping Review'* (Tatlow-Golden et al, 2014). Despite evidence of the profound effect organisational culture has on the attitudes and practices of staff, it is under-researched within the disability field. Piecing together information from the broader health and social care literature, organisational culture is thought to encompass leadership, clarity of management, coherence, support style, rewards for staff input, staff skill and, importantly in the context of deinstitutionalisation, attitudes to change.

Organisational culture is not created in a hierarchical manner, from authority to subordinates; rather it evolves from the interaction of external and internal factors including formal policies and processes and informal stories, rituals and routines. It is likely to play a significant role in disability agencies' response to the reform now being proposed within the disability sector. It may also contribute to the variation in deinstitutionalisation observed in different regions nationally (McConkey et al, 2013).

To examine organisational culture participants from each focus group were invited to generate words and phrases they felt articulated the organisational culture of the agency where they worked. A definition of organisational culture was provided at each focus group to guide the discussion:

> 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).

The words and phrases generated by participants were assigned by researchers into codes and are presented below by organisational type (HSE, large non-statutory, small non-statutory) and region.

	Region 1	Region 2
HSE	Institutionalised Not confident of management Impact of financial cuts No perceived opportunities for promotion Good care Good peer support	Institutional habits Not confident of management Top down management Impact of staff embargo Frustrated and demoralised Paperwork
Large NGO	Institutionalised Management inconsistent Top heavy Short staffed Client-centred Good peer support Team-led	Hierarchical Paperwork Good standard of care Culture of change Progressive
Small NGO	Relaxed management Evolving Progressive Person-centred Impact of financial cuts	Easy to access management The sky's the limit Progressive Person-centred Individualised Paperwork

The responses show a clear difference in organisational culture across the three agency types. HSE staff, working in both institution and community services, perceive the organisation as institutionalised. HSE staff were the only group to report no confidence in management, who they perceive work in a top-down manner. Staff describe feeling frustrated, demoralised, burdened by paperwork and see no opportunity for promotion. The financial cuts to disability services are evident, notably in an embargo on recruitment of new staff. Despite these challenges, participants in Region 1 spoke positively about the care they provided and peer-to-peer support.

Some of these traits are shared by participants from large non-government agencies. They describe an institutionalised culture characterised by inconsistent and hierarchical management styles. They also comment on staff shortages and on paperwork. More positively, this group refer to good care, client-centred approaches, and good peer-to-peer support within a team-led environment. Participants in Region 2, where deinstitutionalisation has progressed more speedily, are more positive about reform specifically refer to the organisation being progressive, embracing a culture of change.

The culture in small NGOs is distinguished by a lack of criticism towards management. Management style here is described as relaxed and easily accessible. Culture in these organisations is progressive and focused on the supported individual. Notwithstanding these positive attributes, financial cuts and paperwork appear as less desirable characteristics, as they did for participants across all three organisational types.

The contrasting ethos of these organisations can be interpreted in light of the location of these organisations on the spectrum from institutional to community-based services. It can also be interpreted within a changing policy landscape throughout a period of economic turmoil. Significant reform is required by HSE services to close their large institutions and other congregated settings. Similar efforts will be required by the large organisations to close clustered living arrangements both

on campus and in the community. The smaller agencies are not immune to the need for reform; while they have no segregated settings, findings from the survey (see Table 4.3) suggest that some settings within the community may be deemed as clusters.

Potential resistance to policy reforms can be identified within discrete aspects of organisational culture. HSE employees take pride in the level of care they provide to people living in institutional settings.

> I don't think anyone would dispute the care, the level of care that the residents get in the centre. You know, if you talk to any family member they would back that up.

The comment that families would attest to the high levels of care provided by HSE is indeed backed up by families using these services who participated in Moving Ahead. Staff working in smaller organisations however challenged the type of care delivered in institutional settings, arguing for a more person-centred approach. This approach reflects an ethos more in line with recent policies promoting greater opportunities to exercise independence.

> Well I suppose, when they're in institutionalised care, it's all routine. Everything was done by routine, so you kind of try and break that. You know, rather than having set times for set things, kind of vary it and go with what they want to do. It's back down to choice.

The relationship between management and staff has been identified as an important determinant of organisational culture and how successfully an organisation can respond to change. Resistance is overcome where managers introduce new cultural beliefs, pass on new values to staff and are seen to adopt the practices they preach (Parlalis, 2011). The commentary from HSE staff in particular suggests that management has failed to communicate its vision to staff:

> They've hired people that are in charge of us that we put our trust, our hope, our everything in. They're abusing the whole system. They're abusing across the whole board. They just really take us and push us aside and whatever they decide goes and we're trying to fix it. We're trying to pick up the pieces and make the best of what we have.

HSE staff also indicated a lack of accountability within the services for those in positions of authority.

> There's nobody coming in and saying 'right, you're to do that' and it works in other places I've worked in. Do you know what I mean? It's just a case of 'it's not my job'.

> I mean, even if I wanted to find out something now, I'm here a year and a half, and I don't know who to go to.

This poor managerial-staff relationship contrasts with descriptions of good peer-to-peer staff support in HSE and also in large organisations, notably so for those in Region 1. These participants spoke of how they valued 'informal' and 'on the ground' support provided by their peers. It may be that these staff perceive a common bond in the challenges they face with peers on a day to day basis whereas their relationship to management is more distant.

Within the context of organisational culture, these findings represent a breakdown in HSE most especially between macro practices (goals and policies decided by senior figures, leaders, Government), mezzo practices (implementation by managers) and micro practices (person-to-person daily interactions between staff and clients of an organisation). Proponents suggest that change is unlikely to be welcomed in organisations where practices at different levels are misaligned (Hughes & Wearing, 2013).

The commentary from people working in small organisations indicates a markedly different relationship with management:

> In a larger organisation, they're [*management*] more taken in with the paperwork and the bookwork, and I suppose they've loads of emails to answer. Whereas, that would also be the case here, but you can actually go and have face to face conversations and that. I think it is an advantage, being a smaller organisation.

It may be that greater access to management facilitated these staff's knowledge of initiatives at macro and mezzo levels. The staff spoke of how their organisations were progressive and evolving, 'the sky's the limit' was endorsed by many at one focus group. These terms suggest that employees in these organisations welcome the opportunity to introduce change into the organisation. This is reflected by commentary which indicated that people working in smaller organisations seemed clear on the direction of their organisation, and how this fits within broader national policy.

> It's quite a progressive organisation, you know, working the person centredness, working New Directions[14] [...] relationships and sexuality education as well [...] it's working an advocacy programme as well. You know it's very progressive for its size.

In addition to the impact of management on organisational culture, many participants mentioned the impact of the financial crisis, generally in terms of staffing and resources. These comments were mentioned in both regions and across all organisational types.

> Well I'm with the service 14 years now, so I started at a time when there was great growth within [*agency name*]. So that was – you were talking about your Celtic Tiger – there was great funding and intellectual disabilities were kind of up there. There were houses opened and services developed and what not. So we saw a great growth during that period and now we're seeing a great retraction.

A lesser theme, and evident only in Region 2, was the issue of 'paperwork' within the culture of the organisation. The general feeling was that paperwork distracted staff from their primary role in supporting people using their services.

> You can be tied up in paperwork, and if you're doing the paperwork what's the person you're supporting doing? What are they doing?

Those working in HSE made specific reference to paperwork associated with care plans. One participant described these plans as 'a bit of a waste'. This view was endorsed by others who felt that while plans were seen as reflecting well on an organisation, they had little relevance for the people they support.

> The care plans are done up like wedding albums, you know, the best one, you know, nearly wins the competition, isn't that it?

It is unclear why only those in Region 2 cited paperwork as an element of their organisational culture. It may be that the greater number of transitions to community living in this area has resulted in more form filling than would be required if individuals remained in situ.

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[14] New Directions is a national policy document outlining a reconfiguration of day service provision for people with disabilities in Ireland. It was published by the Health Service Executive in 2012.

Summary

Staff were asked to describe the organisational culture where they worked. Many take pride in the level of support provided to people using their services, albeit HSE is more likely to contextualise this support within a care framework than the person-centred model espoused by smaller organisations. Key differences were observed in the relationship between management and staff in the differing agencies. The vision outlined in HSE policy documents is not being communicated to staff at ground level. There is no confidence in management; governance and accountability are questioned.

Staff in smaller agencies report closer, informal contact with management and seem well versed in agency and national policy; these staff commend their evolving workplace. Other and lesser themes from the commentary on organisational culture include the impact of the recession and paperwork. These themes centre on the capacity of staff to deliver good support if their time is diverted to other tasks. An area of concern is that some HSE staff do not see merit in the drafting or implementation of personal plans they develop for the people they support.

Taking these findings in combination, staff resistance to change within HSE is to be expected. The macro vision of policies at national level does not translate to activities at the mezzo managerial level. There is no confidence in management, rather they are perceived as taking a heavy-handed, hierarchical approach to imposing change. Without greater buy in by staff it is likely that change will be at best tokenistic, at worst strongly resisted (Hughes and Wearing, 2013; Greenhalgh et al. 2004). This ethos can be contrasted with that from the smaller agencies where change is a key element of their organisational structure.

It is important to acknowledge that the focus groups with staff were conducted prior to a reconfiguration of HSE's implementation of the Value for Money and Policy Review of Disability Services. Subsequent to these focus groups HSE's implementation structures were stood down and six new committees established to address key elements of reform. It is arguable whether staff may be aware of the establishment of these new committees or whether their creation has impacted in any meaningful way on the day to day supports they provide.

7.2 STAFF PERSPECTIVES ON LIVING ARRANGEMENT OPTIONS

Congregated Settings

The definition of what exactly comprises a congregate setting was challenged by some participants, most notably some working within the HSE. These participants highlighted the arbitrary nature of definitions applied to congregated settings. Speaking of a newly-built high specification residential facility, one HSE participant commented:

> If we change the name of it, that's what really annoys me. It's considered a congregated setting as it stands. But if we register it as a nursing home, for people with intellectual disability, it's fine. We're covered. Now that to me is ridiculous, because you change the name of a place?

Three positive aspects were noted to congregated settings; they were deemed to be a preferred option for some, to enable good support, and to provide a segregated environment where needed. Staff from all organisational types stated that individuals who were currently living in congregated settings would prefer to remain in these familiar surroundings.

> This is their home here, which people way up along in the Government forget, that this is their actual home. We mightn't be happy with their home, but they're probably very happy with their little set up, and their little bedroom, and their geraniums and their whatever, do you know? And they need to be listened to.

This view conflicts somewhat with the views of participants with intellectual disability many of whom expressed a preference for smaller scale community living options. Families were also deemed by staff to prefer congregated settings as they provided a safe and caring environment for their relative. Some families in the Moving Ahead focus groups concur with this perspective.

The issue of familiarity of environment was also applied to staff as many participants from a variety of agency types felt that staff working in these settings would prefer to remain:

> You'd have people who work in institutions that absolutely love working there and would fight tooth and nail not to be moving to community housing.

Congregated settings were deemed a suitable environment for people with high support needs who could access all amenities on site and could walk the grounds for recreation. Interestingly, this theme was only raised by HSE staff working with institutionalised settings. HSE staff were also the only group to cite the seclusion of these settings as an advantage for some individuals with high support needs.

> Some of the clients, they are still within the service here but they've moved down to say, we'll say they've improved, so they've moved to an open door unit. Single bedrooms. I mean we still have two units that are locked, but it's because of the type of clients that are in it, and it's for their safety. Every other unit is open now. Where they were all closed, I'd say, except for one, years ago, they were all closed. Now there's two, for the safety of the clients that are in there. Because they would wander and, they can wander out onto the road.

The negative aspects to congregated living were generated by participants working across all three agency types. Participants felt these settings were incompatible with person centred planning, reflected an outdated model of support, and contrary to the opinions expressed above, were unlikely to be a preferred option for people with intellectual disability.

> I supported a person to move out of a congregated setting and he described it as a prison himself, so that says it all really.

Similar to the commentary from people with intellectual disabilities, those who were critical of congregated settings expressed their views with emotion:

> Whereas our congregated setting – dormitories – it's like something out of the dark ages. And that's not a word of a lie. And I would put my hand on my heart and I would say they are the forgotten creatures of [*agency name*].

Congregated settings divided opinion among staff. Those working in HSE institutions were considerably more positive about these settings than those working in other agencies who felt they were incongruous with personalised supports.

Clustered Living Arrangements

In a similar pattern to the commentary from people with intellectual disabilities and family members, staff discussed definitional issues regarding clustered living arrangements. A discussion in one

smaller agency ensued as to whether a group of agency properties on one road could be considered a cluster if the immediate neighbours did not have disabilities. Staff at HSE also found this a challenging notion:

> You see, if you bought a row of houses together, and you were able to house 15 people, in six houses together, they [*HSE*] will still consider that a congregated setting. Yeah, because they're together. Which to me in the era we're living in, with the constraints of money, is absolutely ridiculous.

The dominant response to clustered housing however, including community clusters, was that they would be 'mini-institutions' where 'only the roof' of the institution would be different. Participants from all agencies suggested that the residue of institutional policies and practices were likely to be carried forward to clustered living arrangements. There was also consensus that people living in clusters would become stigmatised in their communities. Both staff and individuals supported in these clusters were thought more likely to rely on each other than on the local community, limiting any opportunity for community inclusion.

A less dominant theme, and one attracting mixed opinion, was that of clustered living arrangements as a vehicle to prepare people with intellectual disabilities for a life within their community. These comments were specific to campus-based clustered settings and were made by staff from both HSE and small organisations.

> Just if they're coming from the congregated setting. Let's say if there's an actual village set up where they're let's say growing their food or they're actually working and preparing for actually going in to independent living. That would be a good idea, kind of gradual phase.

Others argued that the aspiration to move on to more independent options was rarely realised. In these staff's experience, individuals supported in clusters had become overly reliant on staff support and were reluctant to try less supported options.

Clustered living arrangements were thought to be a preferred option for many stakeholders. For staff themselves, clusters provided easy access to other staff and this advantage was acknowledged by many participants. Families and people with disabilities were also thought to favour cluster settings; the responses from these stakeholders in *Moving Ahead* would support this view. Families in particular were thought to associate clusters with higher levels of staff support.

> The majority of our clients, and their families want clustered […] they don't want their children to go to independent living. Because there's way more support available in clustered settings.

Interestingly, participants from one NGO organisation in Region 2 (making greater progress to deinstitutionalisation) commented that their organisation specifically chose not to buy adjoining or houses within close proximity in the community on the basis that *'they didn't want to have any cluster of houses with people with learning disabilities all together'.* This observation reflects the greater numbers of people living in dispersed community housing in Region 2 who participated in the Moving Ahead survey (see Table 4.3)

A final theme emanating from the discourse on clustered living arrangements was the underlying relationship between an individual's support needs and their suitability for clustered living arrangements, specifically campus-based options. Staff working in both HSE and large organisations felt that some individuals with high support needs could not be appropriately supported in the community. This view was not endorsed by people working in small organisations.

> It definitely would be beneficial for certain people and would be necessary. Whether it's for behaviours that challenge or other medical needs or whatever. […] because the supports are there, and it works. We

have tried to move certain people from the cluster out to the community, and it didn't work for them. They didn't have supports.

Staff opinion on clustered living arrangements was mixed. Many felt these environments retain institutional features and are stigmatising; for others they meet the needs of those with more complex disability or those who require a stepping stone to community living.

Community Group Homes

Definitional issues also arose in the classification of community group homes with a number of staff questioning whether they reached the criteria for clustered housing in the community:

We've got two [*community group homes*] together at the moment because it was one big home and they split it into two. And one of those is almost semi-independent living.

Four key themes emerged from staff commentary on community group homes; mini-institutions, forced relationships, environmental aspects and stakeholders' preferences. The most dominant theme was that of community group homes as mini-institutions. Many staff commented that community group homes afforded little autonomy for the people who lived there; rather the staff were perceived to exercise control as they wished.

But a lot of the time group homes are run by the staff, and it's the staff's house, and it's not the people's houses. It's the staff's houses. And there may be two or three dominant staff or a dominant manager and they run it the way they want to run it, and if they leave people's days are dictated by who comes in the door and what routine you have to go by now. Nobody lives in their home that way. That's not the way my home's run.

Examples were given of poor staff practices where high staff turnover and staff holidays created a far from homely atmosphere. Staff also cited difficulties in providing individualised support to people given the diminished resources of recent years. Staff from HSE and large organisations commented that resources were more plentiful in congregated settings; resources were not available to support people in community group homes engage in community activities.

And they tell you, go out to a community house and you interact in the community and you'll be accepted and there are loads of places to go. There's libraries and there's shops to go to. Sure that's all pie in the sky.

Participants from all agency types commented on the challenges of creating a positive group dynamic for people supported in community group homes. Specific problems arose where an individual within the house engaged in behaviours that challenge. Staff called for greater attention to the referrals routes by which some individuals found themselves sharing a home with a group of people they had never met before. There was little evidence of individuals exercising any choice in their referral to a community group home; rather they were, in the words of one participant *'plucked out of somewhere they've lived for 30 years'.* Many staff were highly critical of the practice of moving individuals into houses on a crisis referral; this practice was deemed unfair on both the individual in question and the other members of the household.

Dissatisfaction was expressed with the physical standard of some group homes. This situation had arisen where existing houses were purchased in 'the boom' but were no longer deemed appropriate

to meet the needs of the individuals. In the current financial climate money was not available to adapt these properties to meet need. The social environment also came in for criticism. A number of participants commented that the expected engagement with neighbours in the community had not materialised. This was largely due to the fact that housing estates were empty during the day. This commentary differs from that of people with intellectual disability who were quite positive about their relationships with neighbours. It also differs somewhat from families who were more cautious in their expectations and feared a hostile response within neighbourhoods.

> I think using the word community is interesting because they don't know their neighbours. They're not part of the community. So why call it a community house?

Community group homes were thought to be a preferred option for families and for people with intellectual disabilities. This viewpoint does not accurately reflect those of the *Moving Ahead* participants: people with intellectual disabilities were positive in their appraisals, but the views of families were more cautious. Interestingly, and in contrast to the perspectives on congregated and cluster options, there was no mention of staff having a preference for community group homes.

In combination, the community home model was generally not endorsed by staff. Essentially, these houses were deemed to provide little opportunities for choice and control for people with disabilities and did not meet their expectation of promoting community inclusion.

Independent living

Definitions of independent living varied among the groups. Some participants equated this model with individuals having exclusive access to a personal assistant; for others it referred to 'floating staff' who were available as needed. Those working in smaller organisations expressed a clear view that independent living could span from full to part time support; at essence was the level of choice afforded to an individual and the person's possession of a tenancy.

> You can live independently with support, you know. You live to the level of your competency, and you may require support but it would still be kind of independent, do you know? Your funding, or how you pay for stuff is like your own.

Staff's discussion of independent living generated three main themes: independent living as an emerging option, mixed responses from stakeholders, and challenges with implementation.

Participants from many organisations, including staff from all three types, HSE, large and small, commented that independent living was being implemented within their organisation. Comments such as *'everyone is being offered it', 'way of the future'* and *'that's where the organisation would want to go'* suggested that, in general, organisations were beginning to embrace this model, albeit that for some organisations this model was in the early stages of acceptance.

> You see we're all dealing with clients at different levels but that there are some people in the organisation that have been given that opportunity. So there's an openness there to developing that situation.

For those participants currently involved in the provision of independent living options, a key benefit of this model of support was that it provided a higher quality of life for individuals at less cost than other living arrangement options. One participant provided a case study of a woman who had, for thirty years, been in receipt of 24 hour staff support. In contrast, her new living arrangement was providing just fifty hours of support a week.

Staff were of the opinion that while many people with intellectual disability would welcome this opportunity, families were more likely to register their concerns. This pattern was reflected in the feedback provided by these stakeholder groups in *Moving Ahead*. Some staff felt that families tended to underestimate their relative's ability to live more independently. At issue for these families was the lack of a 'fall back' if independent living was not successful.

> But the big stumbling block is they cannot say to them [*parents*] if this doesn't work out for people, they can come back. That seems to be the major stumbling block.

Staff in HSE and large organisations were concerned as to how precisely independent living was being implemented.

> They're totally on their own. Making their own decisions. How are they cooking and living for themselves?

These staff were also concerned that individuals would be lonely and vulnerable to abuse. Staff in smaller organisations were aware of these criticisms but felt they were unwarranted, arguing that people living in community group homes had poorer social networks and were not included in a meaningful way in their local communities.

> They're targets, because you know I know – I'm in this business and I know that. And apart from anybody targeting them to take money off them, or steal from them, or rob them, or beat them up, I can never see them cooking a meal.

Staff in HSE and larger organisations were also critical at the haste with which independent living options were being introduced. They were concerned that individuals and their families were being pressurised into moving to more independent options, a finding that is backed up by the families in *Moving Ahead*. These staff were also concerned at the speed with which this model of support was being introduced and the lack of consultation with direct support staff:

> We've been told it's going to happen, and that's just it.

Summary

Definitional issues were raised with many of the living arrangement options; what comprises a community group home for one staff member, may be classified as a cluster or an independent living arrangement for another. Congregated settings, clusters and community group homes were all deemed by some staff to retain institutionalised features, but each was also identified as having merits. Opinion was most mixed regarding independent living options, and was clearly split by level of exposure to this model; those with little experience had considerable concerns. These staff were also critical of the haste and pressurised nature of how this type of living arrangement was being offered to individuals and their families.

7.3 STAFF PERSPECTIVE OF FACILITATORS AND BARRIERS TO COMMUNITY LIVING

The barriers and facilitators cited by staff are presented at different levels from systems' level implementation, to community level, to the level of staff and family support, to the level of the individual. These levels are for presentation purposes and are not intended to be mutually exclusive: many cross cutting issues transect across the levels.

Systems' Level

Virtually all of the issues raised at system level were barriers to community living. Dominating these barriers was widespread concern at the speed and lack of consultation with which some individuals were being moved to new accommodation in the community.

> Repatriation was the key word. If you're from [*name of region*] you go back to [*name of region*]. If you're from [*name of different region*], you go back to [*name of different region*]. This is gone out the window now. Where there's a space, they're sending them.

While these concerns were raised by all participants, they were applied largely to the practices of HSE and large organisations. Representatives from smaller organisations commented:

> 'the difference with what we do is the thought process and the attention to detail'.

Many practical barriers to changes in living arrangements were cited including insufficient capacity of housing within community services, lack of 'back up' services where a community placement brakes down, and lack of consultation with mainstream housing. Interestingly, staff from HSE and large organisations were most likely to discuss these issues within the context of people moving from congregated to community group homes: staff working in smaller organisations were more likely to refer to moves from community group homes to independent living. This pattern reflects these organisations' different stages of deinstitutionalisation.

Finance was also considered a major barrier to community living. Staff supporting people in larger organisations felt that economies of scale played out; the cost of services declining as the number of persons supported rises. Staff in smaller organisations argued the contrary, providing examples where costs were markedly lower where individuals had moved to arrangements with lower levels of support. A related issue was the challenges staff faced in securing discrete funding for one individual moving from a group funded setting, termed 'debundling'. Existing pooled budgets for groups of individuals were not so easily allocated if one person decided to leave the group.

Other financial barriers included the costs of housing which was now seen as prohibitive. Rent allowance, a statutory payment for those of limited income to set against rental costs, was deemed completely insufficient to cover the cost of quality housing in good locations.

> I can go no way, they're not going in. It's damp, it's cold. No. They're a human being. They're not, you know, and then I'd have to obviously go to my superior and say no, they're not going into that accommodation, because you can see that they're going to pay a high cost down the line. You know, there's going to be rats after a while. What are the neighbours like? All those kind of things.

Staff from one small agency acknowledged that the financial impediment to securing housing had resulted in their clustering community properties.

> And then we found difficulty actually sourcing houses that they could rent, which is probably why we have the two independent houses together.

Synthesising participants' comments on the difficulties which arise at the system level, a number of issues can be identified which influence a smooth transition to the proposed new configuration of services. Identified barriers included insufficient planning and timing allocated to sourcing and securing appropriate community-based living options, insufficient consultation on moves, a lack of infrastructure linking disability and mainstream housing services, and finally, a host of financial issues, including insufficient finances to secure appropriate housing in good locations and challenges in allocating discrete budgets to individuals wishing to move. Facilitators included clearer planning and

greater communication at all levels in this process. Many staff advocated that dedicated personnel to be charged with implementing these moves.

> There's no system and realistically if we were going to, if they said *'look do you know what, you have to move ten people out, I'm going to sign this amount of staff to do the transition phase'* which doesn't happen like overnight, which happens over a period of time like it used to do […] then it might work.

Community level

The dominant barrier at the community level was a lack of disability awareness within communities. Participants in HSE and large organisations used terminology such as *'devalued' 'dangerous', 'fear'* and *'stigma'* to describe how some members of society viewed people with intellectual disabilities; a clear barrier to community living. Staff in smaller organisations held a different view arguing that disability services have tended to underestimate the potential in the community to support people with disabilities. They argued that greater exposure of people with disabilities within communities would create greater understanding and acceptance.

A number of staff had experienced barriers in accessing social activities within their communities. They described clear examples where people with disabilities were refused entry to specific community groups. This type of exclusion was not experienced for other activities, such as visiting the GP, and may reflect the previous theme of a lack of disability awareness within the broader community.

> It was a drama group actually. And then they came back and they'd all talked together in the drama group. And they said no, no, we wouldn't be insured for that. Honest to God, yeah! Now I would have, at the time, it wasn't something where I kind of wanted to argue with them […]and that would have been a big learning curve for me like, you know, in terms of the next time, like I would just land in with him and say we're into this!

Some staff mentioned the benefits of individuals moving to a location where they were known, in some cases the person's town of origin. The staff felt that locals who knew the individual and their wider family would keep a watchful eye and would be more tolerant of any behaviours that may occur.

Staff also spoke of challenges they had faced by neighbours who were concerned to hear that people with intellectual disability would be moving next door. Staff felt that neighbours feared that '*they were going to set the pan on fire'*. Small strategies were hugely helpful in allying neighbours' concerns; staff reported that merely providing their mobile number in the event they were needed *'a year later I never heard a word'*. In general, apart from some initial reservation, neighbours were deemed to be a facilitative force. Many good relationships were described, and were reciprocal in nature.

At the community level, the central theme was that of disability awareness. Barriers cited by staff were largely due to a lack of exposure to disability. Local communities and neighbours were, following some initial concerns, an important source of support for people moving to the community. These findings suggest the importance of agencies focusing on harnessing natural community supports that sustain community living over time.

Staff level

At the level of direct support staff, a key barrier was the changing job profile of staff working in congregated settings. Comments such as *'it terrifies me'* illustrate the emotive level of these concerns. Within HSE lack of information was a source of frustration and anxiety:

> We're all worried about our jobs and what happens if this place does close. There's no one that has informed us 'look you have a future'. So you have that hanging over you all day […] because I don't know if I'm going to be here for five years or for another year, do you know, so it's not a great environment to work in with that hanging over you. There's no one informing you.

Staff working in large organisations expressed concerns about changing rosters and about the isolated work conditions in community settings. The support from colleagues, easily accessible in congregated settings, would no longer be available and this was a fearful prospect for people who currently worked in larger settings.

> You could be on your own in the house out in the middle of nowhere do you know what I mean? You've no neighbours. I mean you couldn't walk to a neighbour. Some of them you can. Like it's scary.

Staff working in the community acknowledged these concerns and recommended that staff moving to the community receive appropriate training and opportunities to shadow colleagues prior to their final move.

One specific staff barrier to community living was uncertainty about the role of nursing staff. Staff in one large organisation spoke of their fears that their nursing role would become obsolete. Others commented that nurses would be relegated to *'literally just doing the drug rounds'.*

> I don't think we've any choice. I don't think we've any choice, you know. I think we as nurses have to stand up and fight for our own.

The nurses' concerns can be contrasted with those of non-nursing staff working in a small, community-based organisation. For these staff, any medical supports services were obtained by the generic services available in the community.

> The way I think we're supposed to look at it, we look at these guys is, that they're men on the dole. They get 188 euros per week. If they're sick they go to their GP or other services. And if anyone asks me why wasn't this checked out, I'd say well you're going to have to ask their GP. We only support them to live in the house here. Do you know?

The changing role of support staff moving from congregated to community settings can be considered a key barrier to community living. Many staff working in congregated settings were anxious and fearful for their jobs. Some feared an erosion of their role, others isolation from colleagues. A number of strategies may alleviate these concerns. Staff themselves mentioned the merits of training and of opportunities to liaise with colleagues who had previously made the transfer to community services. These strategies, in combination with greater clarity on future terms and conditions of employment, may address some staff's flagging confidence at the prospect of supporting individuals with disability in dispersed housing in the community.

Individual level

Many staff registered their fears about inadequate levels of support for people living in the community. Without appropriate support *'it fails after six months because there's not someone there to make sure*

it's sustainable'. Insufficient staff, high staff turnover and reliance on agency staff were deemed poor practices which staff believed contributed to a breakdown of placements in the community. Volunteers, a possible solution to these challenges, were deemed equally problematic; a myriad of concerns were expressed including training, insurance, Garda vetting and accountability. For some staff, volunteers were also perceived as a threat to job security. Buddy programmes, where individuals with disabilities are matched with volunteers to engage in social activities, also came under criticism;

> The people who were put forward to be their buddies were 17 and the resident was in their 50s. And the other major problem is they were short-term buddies. So our residents could become very, very attached to their buddy and then, all of a sudden when the programme was finished, the person never got in contact with them again.

A number of participants commented on the relative failure of services to achieve social inclusion for people with disabilities, prompting one participant to state *'we have to do this in a whole different way if we're serious about people going into the community'.* Others spoke of their frustrations in the *'vicious circle'* of wanting individuals to develop natural supports within the community, but not having sufficient staff to promote these relationships. On a more practical note, a number of participants cited transport as a barrier to social inclusion, commenting that those living in more rural areas would not enjoy the same social opportunities on their doorsteps as those in the cities.

Characteristics such as complex medical needs, behaviours that challenge and ageing were all cited as potential barriers to community living, most particularly by those working in HSE and large organisations.

> I think there's other people who have high medical needs, high physical complex needs, life limiting conditions. They're going to be very difficult to try and place. Whereas we are trying to shift from the medical to the more social model of disability but there's always going to be a need for that more medical model for some people in a certain way. They're going to be a very difficult group.

A final theme in staff's discourse on factors at the level of the individual was that of family; mostly, family involvement was perceived as a barrier rather than facilitator to community living. Many participant groups discussed the fear of families who were faced with the prospect of their family member moving to settings which they perceived would provide a lower level of support. Some participants spoke of how family members would vociferously resist attempts to alter current living arrangements.

Summary

An array of barriers and facilitators to community living were identified by staff. The system level process was unsatisfactory for many; moves were unplanned, ill-resourced and badly communicated. The suggestion of dedicated and resourced personnel to manage these transitions would resolve some of these difficulties. Disability awareness was a key issue at community level; many of the barriers came from a lack of exposure to disability. Proposals that individuals be supported to live within their local communities, and be facilitated to harness natural supports would go some way to resolving this challenge. Staff themselves may be identified as a barrier; staff working in congregated settings in particular expressed considerable fears about their job security, job role and reduced contact with colleagues. Training, shadowing and clarity on terms and conditions were some suggestions that may alleviate their concerns. For the individuals themselves, high support needs and

insufficient support were identified as key barriers. Staff called for robust staffing levels and a focus on social inclusion.

7.4 STAFF TRENDS BY AGENCY TYPE AND REGION

Clear differences emerged in the organisational culture as described by staff working in the three agency types, HSE, large and small NGOs. The lack of confidence in HSE management is likely to result in difficulties implementing change in these agencies. In contrast, staff in the smaller NGOs perceive change as a key element of their ethos. These trends are apparent throughout the staffs' dialogue on types of living arrangements and their perception of key barriers and facilitators; staff working in HSE and large NGOs show a greater preference for clustered living arrangements and greater concern regarding independent living options than their peers in smaller NGOs. Given that the bulk of reform is required in HSE and large NGOs, greater consultation is urgently required to ensure buy in from these staff and to pre-empt, as would currently be expected, any resistance.

With regard to regional differences, staff in Region 2, which has made greater progress towards deinstitutionalisation, were more likely to report 'paperwork' as an element of their organisation and less likely to report peer-to-peer support. It is speculative as to why this pattern has emerged but may in some small way be related to greater paperwork and more isolated staff conditions associated with community living. Regional differences were observed in the organisational ethos of large NGOs; those in Region 2 were more positive about reform describing their ethos as progressive. Of particular relevance was the comment in one focus group, hosted in Region 2, that the agency had a policy not to purchase community properties in close proximity as these may be construed as clustered. This observation would suggest that decisions made within agencies themselves, driven by their own ethos, have a fundamental influence on the delivery of services within their region. The implications are stark for those living in these regions where disability services are provided on a catchment basis; choice of provider in some regions is negligible.

Summary findings from Results: The Perspective of Staff

• Organisational culture differs markedly between HSE, large NGOs and small NGOs; the culture within HSE can be characterised by demoralised and frustrated staff who have no confidence in management; staff in large NGOs too were critical of management but also mentioned a progressive culture supporting person-centred values; relationship with management in small NGOs was relaxed and easily accessible fostering values that were closest to recent policy trends.

• Definitional issues arose with all four living arrangements; opinions differed and questions were raised as to what comprised a congregated setting, a cluster, a community group home and an independent living arrangement. Agreed terminology would be helpful to ensure misunderstandings don't arise where terms are used interchangeably.

• Congregated settings generated mixed views from staff. Representative from all organisational types felt that those who lived in these settings, their staff and their families would prefer to remain. Staff in HSE were most positive about these settings. Representatives from all agencies felt these settings were incompatible with person-centred approaches.

• Clusters were generally perceived as 'mini-institutions' which stigmatised people with disabilities and afforded little opportunities for real community engagement; those in HSE and large NGOs were

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more likely to consider clusters as an appropriate option for people with higher support needs. Staff in Region 2 reported their agency had decided not to support clusters within the community.

• Community group homes were generally not endorsed by staff; they too were perceived as 'mini-institutions' affording little choice or control to the people supported in these houses. Staff expressed their concerns about the manner in which groups of people were forced to share a house with little consultation, and with some arriving through crisis routes. Community inclusion was thought to be minimal.

• Independent living was described as an emerging option for many. There was a mixed response from staff, mostly reflecting the greater experience staff in small organisations had in supporting people to live more independently. Staff in HSE and large NGOs were more likely to have concerns about hasty implementation and potential lack of supports, while staff in smaller NGOs were concerned about poor social networks and real inclusion within communities.

• Barriers and facilitators to community living were identified at the level of the system, community, staff and individual. Staff were critical of the speed and lack of consultation in much of the reconfiguration. They questioned whether the receiving community were appropriately disability aware and expressed concerns for their own jobs, and for the inadequate support levels they felt were provided for people living in the community.

• Facilitators to community living included addressing practical difficulties and lack of finance, establishing well-resourced dedicated teams to manage changes in living arrangements, locating people within their local communities, harnessing neighbours and other natural support, providing training and shadowing opportunities for staff, and providing greater clarity on any changes in job terms and conditions.

• Clear differences emerged between the perspectives of those working in HSE, large and small NGOs. HSE employees report no confidence in management, show a preference for more congregated types of living arrangement, and are fearful of the impact on their job. In contrast those in small NGOs have easy access to management and embrace change as part of their ethos. Employees in large NGOs are placed between these extremes. Given the bulk of the reform is required in HSE and large agencies, engagement with these staff is urgently required.

• Differences by region were fewer, with two key differences emerging. Staff working in large NGOs in Region 2 described an organisational culture more positively disposed towards change. One agency in Region 2 had a policy not to purchase community properties in close proximity to avoid a cluster arrangement. This policy reflects an ethos within this agency to promote fully inclusive community living. It is highly likely that the adoption of this policy, albeit not exclusively, contributed to the greater progress towards deinstitutionalisation in this region.

8. Results: The Perspective of Senior Agency Personnel

This section reports findings from nineteen interviews conducted with an array of senior personnel connected to eight disability agencies participating in *Moving Ahead*. An additional agency was included from the seven who participated in focus groups with individuals with disabilities, families and staff. The addition of this final agency increased the representation of agency participation in *Moving Ahead* to 65% of all services offered in these two regions.

The interviewees presented in this section represent a wide range of senior personnel including CEOs, general managers, policy developers and directors. Findings from all nineteen interviews are presented in four sections below: interfacing with stakeholders, views on disability policy, closure of congregated settings and development of community services, and responses by agency type and region.

8.1 INTERFACING WITH STAKEHOLDERS

Much of the engagement between senior agency personnel and people with disabilities using their services was at the point of entry to services. Senior personnel negotiated referrals into their service which in more recent times were typically crisis referrals, often arising within the context of the death of a main carer. HSE and large NGOs appeared to bear the brunt of pressure from HSE commissioners and other organisations seeking crisis admissions for individuals they lacked capacity to support:

> We have a large unit, [*name*], and we are having an admission into that unit tomorrow, which is really against the congregated settings report, but this lady has a dementia. It is a crisis from another organisation and we provide the expert nursing that she needs there.

Senior agency personnel were also involved in the selection of individuals who were offered a change in their current living arrangements. A number of agencies reported having specific committees to oversee these decisions. In the case of individuals moving to independent living options, decisions were typically based on individualised circumstances, often where there was dissatisfaction with current services. One senior manager commented that the agency had taken the approach of *'starting with people for whom the existing system had manifestly failed'* or '*who weren't living the life they could live.'* This decision making process contrasted with that for individuals moving from congregated to community-based living arrangements, typically community group homes. In these instances the decision making process tended to rely on a more formalised process using standardised assessments such as the Supports Intensity Scale.

Region 2 was distinguished by having a regional based admission committee in tandem with internal admission procedures within each agency. This regional committee includes members of HSE and agencies within the region and is hosted on a regular basis. Vacancies that arise in participating agencies are discussed and suitable candidates who may fill these vacancies are identified. According to senior agency personnel in this region, the committee aims to abide by the principle of moving people to models providing greater independence and less support.

The amount of actual contact senior agency personnel had with individuals with intellectual disability varied by agency type. Those in smaller agencies described having more contact, most likely a function of the size of the agency. In general there appeared to be limited contact between senior personnel in both HSE services and large NGOs with the people they support. Across all agencies it

seems that people with disabilities are largely removed from the process of decision making regarding their living arrangements.

The relationship between family members and senior agency personnel was complex; sometimes collaborative, sometimes strained. Relations were strained when agencies communicated proposed changes to a person's residential support arrangements. Senior agency personnel acknowledged the challenge for families in trusting services during this reconfiguration of supports:

> Looking to get families involved you really have to hold their hand, particularly at the beginning, and I think families have had a rough old ride with it, and I don't blame them.

According to senior agency personnel, the main concern for family members is the potential impact of agreeing to a change in residential supports. Senior agency personnel felt families are threatened by any tampering with the implicit "cradle to grave" contract between agencies and families. This concern was universal to all agency types and to both regions. Beyond the immediacy of their own relative, families were thought to fear the broader reconfiguration of services as a landscape where services are less tangible, less valuable and easier to lose. This fear was thought to stem from an inherent mistrust at the highest level and was endorsed by families participating in *Moving Ahead*.

> There is a lack of trust in the state. And so any change is deemed to be suspicious. And what you'll get instead of it will be less good.

Senior managers in the two large service agencies in both regions spoke of changing the relationship they have with family members, namely, communicating to family members a new relationship, which is largely unclear to family members and unchartered, but certainly the severing of an old relationship where there is an expectation of a service for life. As well as proposed policy changes circumscribing the ability of service agencies to admit people to congregated settings, agencies had to communicate to families that it would not be possible to 'readmit' people with disabilities to congregated settings should they encounter difficulties in the community, despite the sometimes intense pressure to 'backfill' vacant places where emergencies arose.

By far the most strained relationship was that between senior agency management and others working in the disability field. Mostly the pressure was from super-ordinates, more senior management or HSE commissioners, but pressure from sub-ordinate agency staff was also apparent. These competing push-pull forces were joined by considerable pressures from trade unions and other external agents. Balancing the competing needs of these various stakeholders, including individuals with disabilities and their families, was a source of significant tension for senior agency personnel.

Relationships with HSE commissioners were characterised by incongruence. Requests by HSE to admit people with intellectual disabilities to congregated settings were thought to violate the policy direction espoused by the HSE's own Congregated Settings report. A number of senior agency personnel commented that while HSE is directing much of the change in service delivery, it is the agencies, and more specifically the senior personnel within agencies, who become the focus of ire for many stakeholders:

> It'll be the organisation will be blamed for taking the hard decision to close [*congregated settings*]. And the politicians and even the HSE will avoid that and they'll try to let you be the last person standing.

Smaller agencies without congregated settings were less 'in the firing line' but faced a different threat. Some felt HSE may amalgamate them with larger agencies thereby diluting their ethos and losing their unique identity. For many of these senior agency personnel, HSE as a commissioning body was deemed unsupportive and all too willing to let the agencies stand in the firing line for those opposed to the reconfiguration of services.

Senior agency personnel felt equally unsupported by agency staff in reconfiguring residential supports, albeit to a lesser extent than by service commissioners.

> The reality is, you had people held hostage by a group of staff […] who were generating lots of overtime, who were spooking families that *'they want to give your brother or sister to another group, and that's to save money and you won't know where'll they'll be and there won't be nurses and the staffing levels will be way down.'*

The lack of support from direct care staff was sometimes manifested through trade union resistance to new working practices; this was particularly so for managers in HSE and large NGO services. These managers outlined how unions blocked changes in rostering, moves to the community, and adaptations in the working practices of staff. For some senior personnel in HSE agencies, the effort of asking staff to change working practices seemed fruitless as staff typically reverted to their union:

> [*staff would say*] 'No, I don't like working at that' even though it's [*their*] grade, it's [*their*] pay scale. 'I'm not going outside of that' […] The union would then come to me and say no. Then I'd go to [*name of town*], to the HR department. The HR department would come back to me and say 'look, we need engagement here'. In the meantime you [*staff*] are not doing the one thing I want you to do.

Looking to the future, unions were perceived to be a threat to the introduction of innovative practice. In the words of one manager:

> The biggest barrier to providing an independent living service or developing it in the future is unions, unions, unions.

A regional difference with respect to unions was observed in the commentary from some senior agency personnel. Specifically in Region 2, which has enhanced progress towards community living, interviewees reported past conflict with unions around the high numbers of nursing staff in the HSE and the low numbers in NGOs. These battles had been fought and *'people had come on board.'* Despite winning some of these historical battles, unions were still perceived as a threat to future service innovation.

These strained relationships between senior agency personnel and other stakeholders occur not only at a time of considerable change within the sector, but also at a time of unprecedented economic austerity. The financial climate added significant pressure to senior agency personnel; many spoke of reductions in staff numbers and non-pay resources. These cuts directly impacted on service provision. Interviewees spoke of how some community group homes are closed at weekends to make cost savings on premium staff payments, despite the fact this is a peak time for leisure activities and use of community amenities. Senior agency personnel commented that constraints around hiring new staff curtailed their ability to create new more individualised posts which would typically offer lower remuneration. The economic downturn did have some benefits, some interviewees felt there was now an increased pool of qualified applicants for direct support roles, and increased opportunities to think creatively about how more can be achieved from less.

Summary

The interface between senior agency personnel and other stakeholders was tracked from people with intellectual disabilities, to family, through to others working in the disability sector. Engagement with people with intellectual disability for those in senior positions focused largely on admissions to services, which in recent times were typically crisis referrals. Decision making approaches differed depending on the type of living arrangement on offer; a more informal approach was used for independent living options. Region 2 was distinguished by having a regional level decision making body. Relationships with families were typically strained as these interactions usually occurred within

the context of a change to support, a prospect generally feared by families. Relationships with colleagues within the sector, whether above or below in the corporate hierarchy were very strained; pressure by those above to take referrals deemed incongruent with recent policy was matched by pressure from staff and unions resisting changes to work practices. Senior agency personnel appeared to be firefighting with little support from any sector. This tense environment was well illustrated in one participant's belief that senior personnel will be 'blamed' for the hard decisions imposed by recent policy. The economic climate has impacted on services, but has also provided an opportunity for more creativity in some areas.

8.2 REFLECTIONS ON DISABILITY POLICY

This section presents general feedback from senior agency personnel to the raft of disability policy introduced in recent years. These policies recommend reconfiguration across the full provision of services including children's services, adult day services and adult residential services. This section outlines the general response to this reconfiguration; specific commentary on the policies to close congregated settings and develop community services is presented in later sections.

The discourse from senior agency personnel regarding these policies reflected the location of these agencies on the spectrum from congregated to individualised support. Some agencies perceived themselves ahead of the policy curve. These agencies now focused on the development of new practices to accommodate highly personalised supports. In contrast, other agencies clearly struggled to meet the basic expectations of new policies. There were some references to inter-organisational efforts to respond to policy; these were more typically instigated by smaller agencies. In contrast, larger organisations were more likely to work in isolation to address their response to recent policy.

A dominant response to these policies was a sense of disappointment in the support and strategic direction offered by HSE. These committees were seen as largely talking-shops with little sign of action. Some senior agency personnel called for greater direction from these committees to make agencies accountable for their progress. Others felt that an overly prescriptive approach would be unhelpful as the agencies could make greater progress without interference from an external source. Both perspectives were united in their perception that the committees were ineffectual. As previously noted, these committees were disbanded following the interviews conducted in *Moving Ahead*. A new structure comprising six committees targets various aspects of implementation. It is open to suggestion whether this reconfiguration will provide the level of strategic direction called for by stakeholders.

Many senior agency personnel described the recommendations of these policies as impractical; insufficient finance being the main challenge. Senior agency personnel were adamant that new services could not be developed cost neutral; additional funding was needed. A related issue, also mentioned previously by staff, was the urgent need for a resource allocation model that would calculate personal budgets for individuals with disabilities. These budgets would enable individuals to move to more personalised services using a 'money follows the person' framework. Without identifiable and transferable budgets individuals were unlikely to realise the type of innovative supports espoused by recent policies.

Senior agency personnel also spoke of their frustrations regarding the level of control they could exercise over their own agency budgets. As staff salaries were protected under national pay agreements, the only changes that could be made to internal budgets were related to non-pay budget areas which comprised a significantly smaller proportion of the agency budget. Many high level personnel felt their hands were tied to affect any reconfiguration within their service without more

flexibility on how they could spend their budget. The example by one interviewee from HSE illustrates the frustrations of many:

> Under HIQA's standards every resident is entitled to their holiday and now under HSE rulings and under the financial containment that we have, if they're going on a holiday, it has to be cost-neutral. Now how can anyone go on a holiday that's cost-neutral?

The constant need to reduce costs and introduce cost-efficiencies at a time of significant reform had the optics of suggesting one led to the other, an unfortunate outcome according to another interviewee:

> And what has clouded some very good stuff in the policy has been the economic, so people identify one with the other you know.

Summary

In general, the response to national policy was that the direction was commendable, but the implementation was poor. HSE provided little direction other than the establishment of a plethora of committees which were deemed largely ineffective. Interviewees felt some agencies hid behind these committees using delays in progress to mask their own lack of action. The national financial crisis meant that additional funding, deemed necessary to implement policy recommendations, was not available. Moreover the simultaneous introduction of policies and financial cuts created an optic of a causal link between the two. Many interviewees called for greater control over their own finances to enable them implement change.

8.3 CLOSURE OF CONGREGATED SETTINGS AND DEVELOPMENT OF COMMUNITY SERVICES

Two areas are discussed in this section; the response by senior agency personnel to the policy of closing congregated settings and an analysis of the main barriers and facilitators identified by these stakeholders to the closure of congregated settings and the development of community-based services.

Response to policy of closing congregated settings

Only those interviewees from HSE and large NGOs were currently involved in the closure of congregated settings, albeit some personnel from smaller agencies had previous experience both in Ireland and internationally of winding down large facilities. The opinions of senior agency personnel, in common with individuals with intellectual disability, family members and direct care staff, seemed to be mediated by their own experience; interviewees typically promoted the model of residential support provided by their own organisation. One interviewee, surprised that senior agency personnel in another organisation promoted community clusters, remarked:

> Yeah different opinions. It seems to be to me what area you are working in is dictating your view, which is interesting because you would think at our level that people would say. 'This is what I have, but I really would see better…'

Senior staff within small organisations fully endorsed the closure of congregated settings; the proposal was non-negotiable:

To me, there's only one place to live and that's in the community. There's no options there. So it's about finding the right space for that individual.

This position contrasts sharply with that from senior personnel delivering HSE services. These staff endorsed community living in principle, but struggled to bridge the gap between current provision and that espoused by recent policy. In the commentary below from a senior personnel in HSE, both the current services and the proposals for reform fall well short of that advocated by HSE's own policies:

We're coming from such a low starting point that we'd take clustered community settings as OK. We've dormitory style accommodation in 2013 and it should not be there.

Attitudes to capital programmes to build up community capacity also differed by both organisational type; smaller organisations tended to advocate for the separation of housing and social supports and had no plans to increase housing stock:

Our core business is not to be doing property management if there's somebody else doing it.

In comparison, the HSE and large agencies were more supportive of new builds, especially for people with high support needs moving from a campus to the community. In light of moves towards more personalised services, and international trends notably in the UK advocating the separation of housing and social care, capital investment by disability agencies in property may be deemed a retrograde step.

These clear trends by agency type were also matched by a regional trend. This trend was observed in the commentary provided by senior agency personnel working in large NGOs in the two regions. These agencies are of particular interest as they represent, by definition, a large quantum of the services delivered in their region. They are also of interest as they represent the agencies within the voluntary sector which have most work to complete if they are to meet the recommendations of recent policy. The quote below represents the view of a senior personnel working in a large NGO in Region 1 (region which has achieved less progress towards deinstitutionalisation):

We would contend that you need a range of options and some of the things we provide, maybe some of the congregated settings, the clusters, the modern clusters as we call them, they will have a value and a place, so we kind of advocate you don't throw everything out.

This statement stands in stark contrast to the comment presented previously from support staff in a large NGO in Region 2 who noted that a policy had been introduced not to purchase community houses in close proximity as these could be construed as clusters. These contrasting positions illustrate a clear difference between the ethos driving the delivery of services by large agencies it the two regions. The closure of congregated settings in Region 1 is perceived by some to refer to only large institutional facilities – despite clarity of policy some agencies choosing to interpretation in a manner supporting their own ethos. The focus in Region 2 is on the development of dispersed community housing. Given the size of these agencies, the delivery of their services are likely to be highly influential in the overall trends of service delivery within these regions as observed in national NIDD data (McConkey et al., 2013).

Barriers and Facilitators to Closing Congregated Settings and Developing Community Services

Inspection of the barriers and facilitators generated by senior agency staff revealed many to be interdependent; that is, where systems work well they facilitate change, where not they become a

barrier. For this reason barriers and facilitators are presented in combination in this section using the following headings: planning, engagement with mainstream housing organisations, bureaucracy, the receiving community, staff, families and issues specific to independent living.

Senior agency personnel acknowledged that poor planning could have devastating consequences, not only for the individual in question, but also for the entire drive towards community living:

> I would be concerned that if people are moved out of congregated settings, cost neutral, very quickly, into communities, and they can't fit into those communities […] then it falls back on public opinion, and public opinion as you know drives everything else, and the public would say perhaps they are better off in institutions.

Good planning included graduated moves to the community and full engagement with existing staff whose knowledge and experience would guide the transition. Existing staff should accompany individuals to their new accommodation where possible. These transitions should be planned on a case by case basis and any attempts to move large groups of people *'en masse'* strongly resisted.

> The biggest mistake I saw is that they did it overnight – you need a timeline and a team to support it.

The development of community-based services requires community housing; national policy now advocates that these properties should, where possible, be sourced from mainstream housing. Feedback on the helpfulness of the local authorities in supplying housing in the two regions was mixed, with more favourable comments emerging from senior agency personnel in Region 2 (where greater progress had been made towards deinstitutionalisation). The smaller agency in this region reported:

> We've a direct line to the housing officer and all of our people would be on the housing list.

This comment contrasts starkly with that from the smaller agency in Region 1 where relations between the agency and local authority were poor:

> Yeah, and I get a sense from the people [*local authority*] that they don't want to provide the supports for us. They don't want to provide the housing. They're quite happy that we're where we are, and that we're providing the housing and the supports for people.

A number of elements in the engagement between agencies and mainstream housing bodies were unsatisfactory for senior agency personnel. Examples of poor practice included situations where agencies were told that due to a lack of properties in the region they should not put people on the housing list; housing officers refused to put people on the list regarding them as 'sufficiently housed'; accommodation offered was completely unsuitable ranging from NAMA owned clusters to isolated and unsafe locations. Facilitating factors here included greater collaboration and cooperation from mainstream housing bodies, increased security of tenure and opportunities to make physical adaptations to a property.

Bureaucracy was a key barrier to accessing housing. Navigating the application process for obtaining rent allowance presented several obstacles for people with intellectual disabilities. Firstly, the application form was described as inaccessible. Secondly, some housing officers and community welfare officers appeared resistant to classifying a person in a community group home as 'inadequately housed' and on a more conceptual level, were opposed to people with high support needs receiving financial aids for accommodation from mainstream bodies as opposed to HSE. People with intellectual disabilities who had applied successfully for rent allowance were again disadvantaged when accessing the mainstream housing market. Delays in collaboration between the service agency and local authority led to landlords discriminating in favour of people without

disabilities who could provide monies such as the deposit in a shorter time frame. Organisations were circumventing this barrier by using organisational funds to rent directly from the landlord on behalf of people using their services. As a consequence it was not possible in many cases for agencies to separate housing supports and social supports as originally envisaged by policies promoting individualised support.

Sourcing housing stock was also a challenge for agencies. Some reported spending considerable time trying to source suitable housing. Supporting people with additional physical disabilities or with age related support needs increased the complexity of the task.

Social capital and the receiving community were important considerations for senior agency personnel. Both positive and negative aspects of the receiving community were identified. On the negative side, the dangers of residents being exposed to anti-social behaviour and harassment in local authority housing was a consideration for some senior agency personnel, mainly those from small community agencies. On the positive side, there was some commentary regarding the benefits of living in a community where many of the community were not at work during the day, mostly where people were unemployed or retired. Some stakeholders felt this type of community offered more opportunities for interaction and inclusion compared to neighbourhoods with high rates of employment where there were less people visible during the day, and where neighbourhood residents 'kept to themselves'.

Agencies promoting independent living models reported finding social role valorisation[15] useful in creating 'valued roles' for the person in the community. Practical examples were provided as to how people with disabilities can become valued within their communities; the example below illustrates how people can become valued as consumers, a social role not ordinarily afforded to people with intellectual disability:

> We employ local people so we are a value, this guy [*person supported by agency*] has to be a value, to [*name of hardware shop employee*] he's giving him a lot of business, you know, to the butcher, we shop in the butchers now, we're giving him a lot of business, [*person supported by agency*] is of value to them.

Fading back staff supports as the person accessed community activities, and the promotion of natural supports, was described mainly by those connected with small community agencies and those in social inclusion type roles:

> There was one particular guy – they took him kick boxing, so the staff went with him initially. For two sessions. And then went away - if the staff were there all the time, they'd say *'Oh they're the experts, we'll leave them',* or they'll talk to the staff saying '*is he OK, would he be..'* whereas now they'll ring up the staff and say *'Is it OK if we take so and so to…? He's going to come to the competition with us.'*

Small community-based agencies were distinguished by prioritising social inclusion and harnessing natural supports in the community to sustain inclusion.

The importance of having motivated staff involved in the implementation of setting up new community residences was noted by many senior agency personnel. Many interviewees commented that motivated, proactive employees were far more valuable than employees with more experience and more qualifications but less vision.

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[15] http://www.socialrolevalorization.com/

It's more taking a lead from, say if we had a staff member who's saying *'I'd love to get these people out'* and we think *'well, there's a bit of leadership there, let's build on that '.*

Some interviewees however mentioned that staff had 'sabotaged' prospective moves to the community. This was deemed in some instances to stem from an overprotectiveness of persons supported, a lack of confidence that the person would be able to cope or have a good quality of life in the community, and also, a perceived loss of control by the staff member in the new setting.

So staff can have a huge influence on getting people to agree. […] I could come in and say 'you really don't want that [*community living*]– she's really setting you up – if you do that, one day you're going to be back up here and you're going to be worse. You could end up in [*forensic mental health setting*]*,* or you could end up in ... the police could be called, so you've all this kind of stuff going on as well - sabotage

Staff who had been working in congregated settings for many years were thought to be most resistant to community living. Senior agency personnel in HSE in particular commented that some of their staff had resisted many approaches in the past to move to the community. The interviewees felt it likely that these staff would be particularly resistant to any redeployment, most especially given the greater flexibility they may currently enjoy on a campus setting:

And if that's the case then your base is not this campus anymore and if it's not this campus any more we expect you to go to a house in [town] to support and work with individuals and if that's the case you can't go and pick up your kids from school on your lunch break.

Family members were also identified as a potential source of resistance to the development of community services:

I would say there would be massive resistance to those [*congregated settings*] being closed by families. Massive. Massive.

Senior agency personnel suggested these family concerns were not related to the loss of congregated settings per se, but rather to the potential loss of security, continuity and stability for their family member. Their resistance was compounded by a lack of confidence in the proposed new supports.

For some senior agency personnel the prospect of confronting families during the closure of congregated settings was so daunting as to warrant the continuation of these settings considerably longer than originally envisaged.

I think that we will need to keep everything [*congregated settings*] open and do the change. Because otherwise we'll just have pickets at the gate. And we'll be fighting that battle with families and that's not the battle you wish to be fighting. So we have to keep our shape of what we do now as well as transitioning. **Facilitator: so you're really going to be running two systems?** Absolutely. With diminishing resources.

Specific barriers and facilitators were cited to independent living as a distinct model of community living. Although senior agency personnel's descriptions of independent living were largely uniform, some in Region 1 (which demonstrated less progress towards community living) identified community clusters with floating support, or apartments attached to staffed group homes, as 'supported independent living'. People with intellectual disabilities and staff previously reported a similar definition of independent living aligning it to cluster arrangement. For senior agency staff in Region 2 this concept was dismissed:

> There's one particular person I can think of, and he would have, he would have moved from one of the institutions, HSE institutions, and he would have been supported to move in to another service provider, but he was in a flat attached to a community house and it was deemed independent living!

Senior agency personnel felt that staff and family members were likely to exhibit specific resistance to independent living arrangements. Family resistance was associated with increased perception of risk, fear of having to take a greater role in supporting their family member, and general distrust.

Staff resistance was associated with a de-professionalising of residential support, having to adhere to more flexible working practices such as roster changes, and requirements to relocate and/or travel. Staff fears concerning the vulnerability of the person in the community were perceived as another factor feeding staff resistance.

Some senior agency personnel stated that they were deliberately recruiting untrained staff from outside the agency to avoid confrontation with existing staff. The economic recession had increased the supply of individuals willing to work in a direct support role with less permanency and stability than others working in the disability sector.

Other service agencies expressed a willingness to confront staff who were resistant to this new model:

> I'm all about the individuals we're supporting […] they know it's the way forward. They know it's the right thing to do but they're thinking of themselves and they're employed to support the people in the service. So you have to do your job. I'm sorry!

Summary

Senior agency personnel were acutely aware of the need to maximise the conditions for success for those they supported by ensuring a planned, paced move to the community, with adequate financial and staff resources. Greater engagement with existing staff was recommended to ensure a more cohesive transition. Local authorities and housing bodies were regarded as a key stakeholder and gatekeeper to mainstream housing stock and financial supports for housing such as rent allowance. Agencies had varying success in accessing these supports and there were differences in level of collaboration by region. The importance of choosing a suitable neighbourhood for new community residences was noted, as well as the role of staff and family in supporting the transition. Independent living, a distinct sub-model of community living, was also explored. Staff resistance to the more flexible work conditions was identified as a barrier to providing support through this model via existing employees. Other barriers included family concerns, mainly related to worries about concerns for their relative's safety and the possible transfer of the responsibility of care back to the family. Overall, movement to the community and set up of new community residences widened the net of stakeholders. Many of the barriers to establishing new community residences were a symptom of fledgling processes and systems. The focus should now be to address these issues to ensure a streamlined approach to more personalised services.

8.4 SENIOR AGENCY PERSONNEL TRENDS BY AGENCY TYPE AND REGION

A number of differences arose in the responses of senior agency personnel depending on the type of agency they represented, whether HSE, large NGOs or small NGOs. These differences related to crisis admission, communication with families, and response to policy.

A clear difference was observed with respect to admissions. Senior agency personnel in HSE and large NGOs face considerable pressure to accept crisis referrals to congregated settings despite HSE policy that these settings should close. Smaller NGOs cannot facilitate these referrals as they provide only small scale community-based supports.

Engagement with family also differed by agency type, notably for personnel in large NGOs. Representatives from these agencies spoke of how they had to communicate a new contract to families where lifelong support could no longer be guaranteed and families may be expected to engage in a shared care situation with the agency.

Only HSE and large NGOs were directly impacted by the policy to close congregated settings. Those in small NGOs were adamant that these settings should close. HSE representatives, in contrast, stated that community clusters would be acceptable living arrangements when contrasted with their current dormitory style institutions. These contrasts once again represent the lived experience of participants. Like individuals with intellectual disability, family members and staff, senior agency personnel also gravitate towards the familiar. Differences were also observed in terms of capital investment. Smaller NGOs see mainstream housing providers as the future source of housing and have developed robust relationships with these agents. HSE and larger NGOs continue their investment in buildings, an activity which may be thought to contravene the spirit of newer independent living options where housing and social care are distinct.

Regional differences were also apparent in the perspectives of senior agency personnel. Region 2 was identified as having a referral committee at regional level. All key stakeholders were represented and all vacancies openly discussed. Notably the committee aimed to promote more independent living arrangements. Marked differences were noted in the attitude towards community clusters, an observation also made when reviewing staff commentary. Those in Region 1 indicated that 'modern' clusters were a living arrangement that would continue to be offered. Those in Region 2 had purposefully avoiding properties that may be perceived as approaching a cluster development. Finally, differences were also noted in the level of engagement senior regional personnel had with mainstream housing agencies. Interviewees in Region 2 reported more collaborative relationships with these mainstream agents than representatives from Region 1. In combination, findings from senior agency personnel reveal clear differences that likely contribute to the greater progress towards deinstitutionalisation in Region 2; a high level referral committee favouring personalised arrangements, a policy against community clusters and greater engagement with mainstream housing. These elements are contributing factors to the higher levels of community-based living arrangements in this region.

Summary findings from Results: The Perspective of Senior Agency Personnel

• Engagement with stakeholders was strained for many senior agency personnel; people with intellectual disability were mostly likely to be admitted in crises referrals, families did not trust proposed changes to living arrangements, commissioners requested referrals incongruous with policy and staff and unions were resistant to new working practices.

• The economic crisis had reduced some service delivery but also provided an impetus for innovative and creative practices to emerge.

• The general response to recent policies was that while the move to more personalised supports was admirable the implementation was poor. HSE provided little direction; their committees were seen as ineffectual.

• Senior agency personnel dismissed the notion that the reconfiguration of services could be achieved without significant investment and felt that their hands were tied in making any substantial changes as they hold little control over their own budgets.

• Individualised budgets were identified as a necessary condition for personalised services.

• Responses to the policy to close congregated settings were, as with other stakeholders, mediated by experience; those delivering congregated services were more amenable to these living arrangements, notably clusters.

• An array of barriers and facilitators were identified to the development of community living, the focus here will be on facilitators. Moves to the community should be gradual, individualised and supported by existing staff.

• Mainstream housing should be accessed to ensure people with disabilities enjoy choice in their provider of housing and social care supports. Agencies should promote good working relationships with housing bodies. Mainstream housing bodies need to enhance their services to meet their obligations in supporting housing for people with disabilities. Greater security of tenure is required. Adaptations to properties and access to rent allowance should be facilitated.

• Agencies should work with various stakeholder groups to promote buy-in. The concerns of staff and families need to be addressed. Motivated staff should be encouraged. Natural community supports should be promoted; social role valorisation may be a useful framework.

• Differences in perspectives and experiences were noted according to the different type of agencies interviewees represented. As with previous stakeholders, senior agency personnel gravitated towards the model of service they provided.

• HSE and large NGOs faced specific pressures to receive crisis admissions to congregated settings. Large NGOs also commented more on their communication with families regarding the changing direction of service delivery. Both HSE and large NGOs were more likely to purchase properties while smaller NGOs were more likely to avail of mainstream housing. The separation of housing and care is more likely to be achieved by smaller agencies.

• Different perspectives and experiences were also noted by region. Region 2, which shows greater progress towards deinstitutionalisation, hosts a regional committee to decide on referrals. This committee promotes movement to more independent living arrangements. Region 2 is also characterised by a policy not to purchase houses in close proximity that may be deemed clusters and by greater engagement with mainstream housing bodies. In combination, these elements are likely contributors to the greater progress towards deinstitutionalisation in this region.

9. Results: The Perspective of HSE Commissioners

Six HSE commissioners were interviewed for Moving Ahead. Their commentary is presented in four sections below: the commissioning environment, views on disability policy, closure of congregated settings and development of community services, and trends by region.

9.1 THE COMMISSIONING ENVIRONMENT

These interviewees are responsible for commissioning services within their region. Services include those directly provided by HSE and those commissioned from non-statutory providers, represented in *Moving Ahead* by large and small NGOs.

Commissioners described their immediate working environment as challenging. One commissioner, commented *'we're not fit for purpose'* with another describing morale as *'very low'*. A moratorium on staff recruitment introduced during the economic crisis was causing significant challenges for HSE; staff numbers were markedly reduced, the demographic profile of the workforce was aging without replacement, and any hiring of staff was now on an agency basis through private providers, a practice which incurred considerable cost.

The moratorium on recruiting new staff had specific implications for HSE where a cohort of staff was approaching retirement. In former times the salary attached to an individual retiring from a congregated setting could be transferred to new staff supporting individuals in more independent arrangements. Over time, this process assisted in migrating salaried posts from congregated to dispersed living arrangements. Due to the moratorium however the salary of retired individuals exited the system along with the retired staff member. Commissioners described how this loss of flexibility in transferring salaries reduced their opportunities to divert money to new models of support.

> It means that I'm stuck in the model I'm in, and it also means that there's agency staff coming in to cover staff who've left.

The combination of financial restrictions and a low complement of staff were taking their toll on the delivery of services within HSE. Commissioners referred to HSE *'being left behind'* as NGOs upskilled their workforce and their support practices in line with best practice. In particular, the lack of opportunities for HSE staff to attend seminars and conferences profiling new and innovative support models was seen as a distinct disadvantage, most specifically for direct support staff who were rarely exposed to external influences.

Compounding these challenges was a perception that HSE's own internal communication system was inadequate. Key information decided at national and regional fora were not disseminated at grass roots level within HSE:

> So you're hearing it [*from outside HSE*] and this is HSE business that we should know of! So while they have the structures set up, they have the structures set up where they have the national group, they have the regional, the links aren't happening. So there's much happening within disability services but your links, your system isn't keeping up with it.

Commissioners were also critical of the level of autonomy they could exercise in allocating their budget. Situations arose where commissioners wished to move resources, in many instances migrating funding from high dependency settings to more independent options. Interviewees commented that HSE structures did not facilitate commissioners to disengage funding from their current usage and called for greater flexibility to permit them divert funding to newer models of support.

The commissioners also spoke of a lack of autonomy in responding to either under-performing or over-performing NGOs; they reported having no authority to reward or sanction providers dependent on the quality of service provided. A lack of support from HSE and the Department of Health resulted in commissioners rarely, if ever, withdrawing funding from under-performing service providers.

Within this challenging working environment, the future role of HSE in the delivery of services was unclear. Commissioners spoke of international trends where state bodies such as HSE had removed themselves from the direct delivery of services. A commissioning only role for HSE was predicted by families in *Moving Ahead*. They feared that should this come to pass HSE were likely to commission from private for-profit organisations, a prospect that was universally condemned by families. The commissioners themselves felt a withdrawal from service delivery may provide them with more authority in their negotiation with providers, albeit some were skeptical:

> We all agree we're going to a model of commissioning right but implied in the commissioning is that if you don't deliver I will retract. I don't think the HSE has the b***s for that.

Commenting on services that are currently delivered by HSE, commissioners identified a number of key distinguishing characteristics. Individuals with disabilities supported by HSE were thought to have higher support needs than people supported by NGOs. Commissioners argued that the statutory remit of HSE to provide services meant that other agencies could defer the delivery of services to HSE in cases where they deemed their service could not appropriately meet an individual's needs.

> We still have service providers who are truly integrated into the community with community houses and believe in the ethos and all of that, person-centred planning and all of that, but when things get difficult they're not able to manage individuals and they come knocking at our doors to have people admitted to the institutional-type settings.

Another factor distinguishing HSE services was the lingering influence of the medical perspective from which many HSE services were developed. Commissioners spoke of how some current HSE intellectual disability services emerged from services initially developed to support individuals with mental health difficulties. These services were and remain staffed by nurses with psychiatric training. In time, these services were transferred, sometimes overnight, to 'de-designated units' within intellectual disability services. The commissioners commented that while these services were now under the remit of intellectual disability services, the influence of a medicalised model of disability persisted.

> Most of our nurses are psychiatric nurses. They came from mental health services. They do not understand ID services. Now over the years I'm sure they learned a lot, I'm not totally knocking them but they have a different background, different training.

Relationship with NGOs

HSE's relationships with NGOs were typically long-standing and were renewed annually using the Service Level Arrangements which formalised the contractual relationship between HSE as

commissioner and NGOs as service providers. Ongoing monitoring and quality assurance were key activities for commissioners within this role. In undertaking these duties, commissioners generally spoke of a close and effective partnership with NGOs.

The arrangements between HSE and NGOs were largely historical; some NGOs were providing services within their regions over many decades. The longevity of these arrangements accrued benefits in terms of a well-established relationship between commissioner and provider, but there were disadvantages. In particular, commissioners commented that the long-standing nature of these relationships caused challenges when determining and interpreting annual financial allocations for these providers, a key responsibility of HSE commissioners. The commissioners described how current allocations were typically either increments or reductions to allocations made in the previous year based on a combination of new persons entering or leaving the service or, more recently, financial cuts to the overall budget received by the NGOs. Over time, the original allocation had become indistinguishable from identifiable units of service. Commissioners suggested that the introduction of a zero-based funding mechanism would provide a more transparent and equitable method to allocate funds. Zero-based funding is a bottom up funding model where specific costs are assigned to specific units of service. This type of funding mechanism allows commissioners to reconcile the exact cost of specific elements of a service, and therefore hold providers more accountable for their expenditure.

> Each agency is a legal entity in its own right, so they have their own responsibilities under their company regulations, etc. So within that what you might find is that there's posts that they've created that you have funded and maybe it's a bit obscure after so many years, and that causes its own complications.

In general, most NGOs were perceived to have embraced the change agenda espoused in recent policies.

> They have been quite innovative over the years and would have continuously push[*ed*] that. I think from my own experiences, as I said, a lot of the agencies saw a need and responded.

Commissioners commented that NGO providers accrued certain advantages over disability services which were provided directly by HSE. The independent status of these providers, as non-statutory organisations, facilitated them to introduce new and innovative practices in a manner that would be challenging within HSE directly delivered services which were characterised as being more risk-aversive. NGOs were also perceived to have enhanced relationships with stakeholders such as family members; the non-statutory and more independent status of this sector was deemed to facilitate a more open relationship with people availing of their service.

A criticism of NGOs from a number of commissioners was that while these agencies advocated concepts such as independence, choice and control for the people they supported, the practices of some organisations was deemed to fall somewhat short of these ideals.

> Some organisations look good on paper and talk the talk, and when you get a little bit deeper don't walk the walk.

At issue, for some commissioners, was the monitoring of some of the newer, more individualised services. One commissioner commented that regulatory bodies such as HIQA would be unable to examine anything more than the aspiration of individualised services as outlined in service providers' paperwork. This commissioner argued that the actual practices required to support people in highly individualised services would be too nuanced to be captured in HIQA inspections.

For another commissioner, the move towards more personalised services was compounded by the size of some of these provider organisations. This commissioner commented that the centralised structure of these larger organisations was at odds with community living policies.

> In my opinion you would argue that agencies need to be broken up to achieve that, because if in effect you're going to community, the opposite of community is centralisation and if you have a centralised service and a community there's a mismatch so the question there is can you redesign the agencies, re-engineer so that they're more local-based, more locally responsive. And I would actually believe from experience that local services for local people can actually be better.

The call to dismantle some of the larger non-statutory organisations into smaller services was in marked contrast to another commissioner who argued that there are currently too many organisations providing services. Rationalisation was proposed to address a perception of duplication in the structure of how services are delivered. Some commissioners, for example, commented on the myriad of administrative and managerial posts such as 'director of services' and 'residential managers' all of whom provide highly similar functions within each agency. Pooling these posts across agencies was proposed as a method to reduce duplication of effort, albeit that it may inadvertently, as highlighted in the quote above, also reduce customer choice.

Commissioners' discussions regarding the status of NGO service providers were contextualised for some commissioners within a framework of 'empire building'. These commissioners spoke of how some NGOs had, over a period of many years, moved from an initial focus of providing direct supports to small numbers of individuals, to a focus which was primarily concerned with maintaining and validating organisational structures. Some commissioners expressed concerns that organisational drives towards quality assurance, person-centred planning systems and staff training, among others, may have little impact on individuals receiving services despite the considerable investment in their implementation. One commissioner speculated whether a focus on growing the organisation would influence some providers to prefer ownership of the housing they provide for those availing of their residential services. These properties, in contrast to social housing or private rental tenancies, may be perceived as an organisational asset.

> So we've a lot of organisations with a lot of capital. Then you have a lot of houses, a lot of buildings. And it's like an extra valuation on their organisation.

An underlying theme in this discussion was whether a conflict of interest existed between organisations who strove towards expansion and greater professionalisation, and individuals with intellectual disability who sought greater choice and control over the personalised supports they receive.

Economic Pressures

The impact of an economic climate characterised by recession, austerity and financial cuts pervaded much of the commissioners' commentary. A lack of new money entering the system at a time of unprecedented change, combined with the moratorium on staff recruitment impacted on service delivery. One commissioner reflected the views of many when explaining how under-resourced services were to meet demand:

> I mean there's a significant […] under-funding across all the services and we have crisis, emergency, residential requirements. We have nowhere to place people now.

Residential supports in particular were deemed by some commissioners to be a service that could no longer be offered to individuals with intellectual disabilities and their families. Those seeking residential supports were being informed by some commissioners that HSE was no longer

responsible for the provision of housing for people with intellectual disabilities. Individuals were now being directed to mainstream housing bodies to secure social housing. Others, typically presenting in crisis situations, were being offered respite services. Commissioners commented that this practice was now becoming so widespread that respite services were essentially becoming blocked by individuals for whom no long-term residential living options could be sourced. Respite services were identified as being squeezed in both directions as they stemmed the tide of those seeking residential supports, and they were low hanging fruit where financial savings could be achieved.

The lack of transparency in funding cited previously placed commissioners in a situation where they could not contextualise where cost-savings could be achieved. Nor could they validate requests for additional funding.

> I've sat in a room with a parent who was extremely upset with the HSE and the provider, and the provider saying to all of us "you need this service. we'll certainly give you this service if the HSE gave us money". Now that happens, and it happens more so in times of cutbacks. Now what wasn't mentioned there was the service were already getting a couple of million from the HSE.

Notwithstanding the significant impact of financial cuts to direct service provision, and the implications of a curtailment of services for individuals and families presenting in crisis, many commissioners cited positive aspects to the austere economic environment in which services were being delivered. Many organisations were observed to be coping well with the financial restrictions with quality services continuing to be delivered through efficiency implementations. Commissioners spoke of 'doing more with less', of 'creative' and 'cost effective' solutions which would not have been considered throughout the economic boom. A tightening of budgets had, in some organisations, altered the criteria for access to residential services which resulted in prioritisation of need over want. In addition, the recession had provided a forum for introducing the notion of 'shared care' where family members and service providers would become partners in supporting individuals with intellectual disabilities.

Summary

In combination, HSE commissioners described a challenging and under-resourced working environment. Their role in both direct service provision and in commissioning was contextualised within a period of economic austerity. The general consensus was that HSE would, in time, become a commissioning-only body following patterns observed in other international jurisdictions. Greater autonomy in moving resources, incentives for well-performing providers and withdrawal of funding from under-performers were all deemed to empower commissioners obtain high quality services from NGOs. Commissioners also called for administrative infrastructures and resource allocation systems that would clearly link expenditure with identifiable service units. Armed with accurate information, commissioners would be better placed to negotiate costs with service providers. Systems to improve internal communication were also sought. Finally, a significant challenge for commissioners was the moratorium on recruitment resulting in an exodus of senior and experienced staff. These challenges are some of many within which HSE will take a leading role in the implementation of a major reconfiguration of disability services.

9.2 REFLECTIONS ON DISABILITY POLICY

All commissioners perceived the new disability policies as providing appropriate and welcomed guidance for the future development of disability services in Ireland. In particular, the policies were

deemed to facilitate a dialogue with other stakeholders regarding the move towards more personalised services.

> I think the Congregated Settings is a real driver for change. I have to say, wholeheartedly agree with that.

Two core themes were generated from commissioners' discussions; issues regarding communication of policies to all stakeholders, and issues of implementation, most notably the need for resources and the need for leadership.

At best, communication of these policies was described as variable, despite the major significance of their content for both HSE and other stakeholders delivering or receiving disability services. Mechanisms to impart policy information to staff, such as asking them to sign off on having read new policies, were found to be ineffective resulting in an ill-informed workforce. Commissioners too experienced challenges in receiving information regarding new policies. Indeed, some commissioners suggested that HSE's communication with external bodies was more effective than within its own ranks:

> The information doesn't come down in a coherent, organised fashion where everybody's up to speed about what's going on. A lot of the time you get to hear about stuff through the voluntary agencies connected to organisations like, the Disability Federation, the DFI, and they're being told through official HSE channels what's happening and it doesn't get fed down through the structures.

The lack of clear communication on these policies caused a level of confusion for commissioners who struggled to interpret how new policies should or could be applied.

Commissioners also spoke about the role of communicating these policies to stakeholders beyond HSE. For one commissioner the responsibility for disseminating these new policies to non-HSE staff and family members resided with NGOs themselves or with advocacy organisations such as Inclusion Ireland. This commentary reflects previous commentary from senior agency personnel who argued that HSE left agencies to face the ire of families who were opposed to any reductions in supports. One interviewee shared a personal experience of meeting the ire of families face to face:

> As I said, my one experience of going out to front this wasn't a very pleasant experience. I got loads of apologies at the end of it but I tell you that people were … I'm just lucky my name wasn't at the end of the report, that's all.

Commissioners were asked specifically about their views on the implementation strategy for the HSE Congregated Settings report which calls for the movement of over 4,000 individuals with disabilities from congregated to community-based settings. Commissioners commented that there were no plans for a standardised implementation strategy for the closure of congregated settings across the country. Rather, implementation would vary locally.

> For the HSE congregated settings, very little has happened by way of a higher power driving the implementation so you were left to your own devices.

Implementation was thus described in terms of a local consensus by various stakeholders as to how the move towards community-based services might best be achieved.

> It'll just evolve.

> Well my understanding is that it was up to every area to progress from congregated settings in whatever resources that they had.

Commissioners were asked whether a more prescriptive approach to implementation would be welcomed, or whether the local strategy, as being undertaken, was more effective. While some commissioners welcomed the autonomy and flexibility of the local approach to implementation, others argued that ongoing monitoring would be essential to ensure milestones were met. Several commissioners called for measurable indicators of progress which should be made available in the public domain. There were also calls for specific named individuals to be made accountable for progress.

Concerns regarding the lack of dedicated resources to achieve implementation were expressed by all commissioners. In particular, commissioners commented on the need for more staff, and indeed new staff, to ensure effective and timely implementation of these policies. A number of commissioners expressed concern as to whether implementation could be achieved cost-neutral, that is without significant new funding being made available to support such a large-scale reconfiguration of service delivery. A one million euro fund to assist implementation of the National Housing Strategy, while welcomed, was not deemed sufficient to source the volume of housing now required for people with disabilities.

Despite these challenges, a number of commissioners acknowledged that some provider organisations had already made significant gains in implementing some of these policies. These agencies were perceived to have embraced change as a part of the broader culture within their organisations that sought more personalised services for people with disabilities. Implementation might therefore be contextualised as a natural extension of the values espoused by these providers.

One specific aspect of implementation was raised many times by commissioners, that of leadership and more specifically, who was leading the implementation of these reforms. A number of commissioners commented that no specific agent seemed to be responsible for leading out on the proposed reconfiguration of services.

> Well from where I'm sitting there is nobody driving it.

Most commissioners acknowledged that HSE held a leading role in implementation, albeit including a proviso that HSE was only one of a number of key players involved in this reconfiguration of services. One commissioner, acknowledging the criticism by some provider organisations that HSE was not showing sufficient leadership in implementation, commented that this criticism may be an attempt by some providers to deflect attention from their lack of progress in moving towards more personalised models of support. A similar criticism was directed at some HSE staff who were deemed to deflect responsibility for implementation while awaiting instruction from higher levels of management within HSE. This reflected the views of several interviewees that implementation would be subject to a phenomenon they described as 'death by committee'. A number of commissioners had previous experience of how initiatives within HSE had been stifled in this way. While some commissioners perceived such delays as stalling progress on implementation, other commissioners were reluctant to commence an implementation process without receiving clear instruction at national levels.

The frustration at lengthy delays in establishing the basic infrastructure for reform within the disability sector led one commissioner to question whether these policies were prioritised within HSE. Given the scale of the proposed changes, this commissioner asked why disability was not allocated a national directorate of its own, as was the case for Mental Health, in the recent restructuring of HSE.

Summary

In summary, commissioners' discussions regarding the numerous disability policies emanating in recent years focused on two core themes of communication and implementation. Clear gaps in communication were evident at multiple levels within and among relevant organisations. Implementation was generally perceived as an evolving process which varied by location. For some commissioners this local approach yielded benefits in terms of flexibility and autonomy. For others, these benefits were overshadowed by the possibility that without appropriate transparency and monitoring little progress may be achieved.

All commissioners expressed concerns as to how such a radical reform of services could be successfully implemented in the absence of additional resources. In addition, commissioners argued that while HSE would undoubtedly take a leading role in driving implementation, HSE was just one of many stakeholders whose input would be required to ensure success. Criticisms that HSE was tardy in establishing the necessary infrastructure for implementation, and that HSE may engage in a process of 'death by committee' were also matched by a call for greater guidance on the implementation process, a call which may reflect the poor communication systems previously cited.

9.3 CLOSURE OF CONGREGATED SETTINGS AND DEVELOPMENT OF COMMUNITY SERVICES

Many barriers and facilitators to the closure of congregated settings and development of community services have been identified by previous stakeholder groups in this report. To avoid duplication, only key issues relating to commissioning and the broader introduction of community-based services shall be reviewed here. These issues can be categorised as leadership, the commissioning infrastructure, communication, and facilitating change within NGOs.

Leadership

Leadership is required at the highest level in HSE to drive reform. In the absence of leadership implementation is left to the responsibility of individual personalities, some more motivated than others:

> Very little pressure from higher authorities - I've got very little pressure for me to progress. We get monies every year for day services for people and we keep popping them into the same type of traditional *[services]*.

The challenge is that individuals in a position to implement change are likely to gravitate towards the model of support they are most familiar with. This pattern has been ably demonstrated from many stakeholder groups in *Moving Ahead*. Leaving individuals to their own devices is unlikely to drive through the level of major reform proposed for the disability sector.

If the closure of congregated settings and development of community-based services are to avoid the 'slow and tentative drift' already noted by the Value for Money and Policy Review of Disability Services (2012), leadership must be taken, and must be seen to be taken. The current HSE approach observing agencies 'evolve' towards reform is at best likely to lead to slow progress, at worst to sustain the varying progress towards deinstitutionalisation observed nationwide.

> I think the situation is that the ideology is clarified and understood. The policy is in place. What is badly needed is a corporate prioritisation, an accountability for it. So therefore my opinion is that nothing changes unless there's exposure and transparency.

Opinion was mixed by HSE commissioners as to how prescriptive HSE should be regarding implementation. At a minimum an overall implementation framework is needed to spearhead this level of reform (Mansell et al., 2004; Meyers, Durlak & Wandersman, 2012). This framework needs to incorporate the interconnect elements of practice from policy (mezzo level) to systems (mezzo level) to individual day to day practices (micro) (Hughes & Wearing, 2013). Currently policy is plentiful but its application within disability systems and within day to day practices is tenuous at best. HSE must bridge the gap between policy and systems, and between systems and day to day practice. The considerable gulf between HSE policy and practice does little to facilitate stakeholders engaged in day to day practice to see value in the proposed reforms.

Implementation plans themselves may become a barrier to progress if deemed irrelevant and impractical by stakeholders. Plans may be perceived as top-down enforcement which is typically resisted by public sector employees (Parlalis, 2011). To have integrity implementation plans must be seen to reflect HSE's own beliefs and practices regarding deinstitutionalisation.

> You have to have a commitment from the most senior in the HSE. If that's not there, it ain't going to work. It's not there at the minute, because the drive is not there – there's no drive. Go back to who's driving this.

Commissioning Infrastructure

Currently there is virtually no visibility of how the proposed reconfiguration of services will be implemented in practice. The minimal infrastructure in place has been described as ineffectual 'death by committee'. Commissioners called for a standardised approach to implementation with clear governance, measurable progress indicators and named individuals responsible for progress.

> I think the situation is that the ideology is clarified and understood. The policy is in place. What is badly needed is a corporate prioritisation, an accountability for it. So therefore my opinion is that nothing changes unless there's exposure and transparency.

This lack of accountability occurs simultaneously with frustrations expressed by commissioners regarding the level of authority they have to encourage change. A significant barrier to supporting reform was the commissioners' inability to reward good practice and sanction poor service delivery for the larger service providers (known as Section 38). This was not the case for Section 39 agencies:

> In Section 39s you have a little bit more control. You can actually take, if they don't reshape the services the way you want you can actually take their money.

One commissioner described a preference for purchasing some services from private agencies on the grounds that funding could be withdrawn with speed where services were not deemed of sufficient quality. By empowering commissioners to exercise greater authority over the services they commission agencies become more accountable for their funding and may become more incentivised to implement reform.

A related barrier was commissioners' inability to divert funding to different models of support. The moratorium on recruiting new staff meant that commissioners could not create new posts within more personalised services. Not only are new staff required, they are required to fulfil the specific brief of

more independent community-based supports. HSE needs to facilitate commissioners to guide the recruitment of appropriate support staff towards individualised services.

A significant barrier to reconfiguring the staffing profile of services, notably HSE and larger NGOs, is the complement of nursing staff many of whom have training in mental health. Commissioners called for a decision by HSE as to how these staff in particular can be facilitated to stay within disability services, if that is their preference, or to be redeployed elsewhere within the health services.

Commissioners frequently commented on the lack of good quality data. This challenge is not specific to disability services but rather widespread throughout HSE. Despite repeated calls for improved data systems within HSE's own National Service Plans progress is slow. Accessing data on allocations to NGOs and aligning these to specific units of service is particularly problematic:

> The service level arrangement gives you a lot of detail so I know how many units are in [*name of agency]* and I know how much money I'm giving them. What I couldn't do is take it down to the individualised money.

Schedules within Part 2 of the Service Level Arrangement contract between HSE and NGOs is the appropriate mechanism to capture this information.

A major facilitator to increasing funding transparency is the development of an agreed national resource allocation system based on individual support need. This system would address the challenge noted by many commissioners trying to reconcile costs to individuals. A resource allocation system would determine a unique budget for each individual from which services may be commissioned using a range of mechanisms from direct payments through to agency based management of budgets. Inherent in this system is the determination of unit costs for specific units of service, typically based on staffing costs. This system is currently being explored by the National Disability Authority (NDA) albeit commissioners were critical of initial proposals:

> When I went along to the NDA to the presentations of it and the guy who presented, he seemed to know an awful lot about the elderly but didn't seem to know about disabilities.

Communication

The 'plethora' of recent policies, while generally welcomed as instruments for change by commissioners were deemed to have been presented within a short time scale causing confusion and fear. These concerns were exacerbated by poor communication. Commissioners themselves commented they were unclear of their obligations under these policies. They also acknowledged that communications to staff within HSE had left them generally uninformed.

Good practice in introducing radical reform in health care organisations suggests that staff need sufficient information on changes at key points in the transition: at preparation stage to outline how they personally will be affected; at introduction to provide training on how to incorporate change into their daily work; and ongoing to provide feedback on their continual adoption of policy (Greenhalgh et al. 2004). There was little evidence from commissioners of this level of communication.

> There's definitely big problems with the communication pathways and I think that will impact on implementing policies.

HSE strategy seems to put the onus on employees to inform themselves about these key policy shifts; staff are asked to sign off when they've read a policy document. As the quote below reveals, this strategy is tokenistic at best.

> I noticed that she had it signed that she read it and understood it, so I asked her about it. And she didn't know what I was talking about.

A more beneficial strategy may be to facilitate staff to attend conferences and seminars where innovative practice is demonstrated (Mansell and Beadle-Brown, 2012). This strategy was acknowledged by commissioners as an effective vehicle to not only inform staff about policy but also to demonstrate how policy can be implemented in practice. The economic situation however meant that access to these events was very restricted:

> When I go to conferences, which is very few, I'm seeing the same people. They're the CEOs. They're the area managers, the regional managers, they're the social workers, they're, you know, you don't see front line staff there. So they're not hearing, or they don't know what's going on in the world of intellectual disability.

The opportunity to witness at first hand the impact of more independent living arrangements may alleviate some of the concerns stakeholders such as staff have in implementing reform. Practical demonstrations reduce perceptions of complexity making change more likely to be adopted. Currently it seems that the very audience who could benefit most from exposure to these demonstrations are the least likely to attend.

> Yeah, there's no point rolling out demonstration projects if they're not demonstrated to the audience that it matters. So I think that's a huge problem and probably where we're falling down.

Facilitating change within NGOs

HSE has influence to facilitate real change within the delivery of services. Notwithstanding the considerable progress made by some agencies in promoting more independent and individualised support arrangements, commissioners acknowledged that some NGOs still operate from a care ethos:

> They are cared for nearly within an inch of their lives. They are minded and protected. They're fed. They're eating well. They look well. They, you know, they just look very, very different. Very healthy and all of that. And people think their job, that's their job done. That's where it ends. It's when you bring it to this notion of the aspirational kind of you know, what about, you know, what does she do outside of here? What does she do? Oh we can't go there because we can't or we don't have transport.

It is critical that organisations are supported to achieve a paradigm shift for themselves from a culture of caring to a culture of support. According to Schalock & Verdugo (2012) such a fundamental shift in culture requires support at all levels. HSE may facilitate this change through acknowledging the organic and often rather messy format within which change is ordinarily introduced into organisations. For Greenhalgh et al (2004) staff do not simply adopt change from management rather they experiment with it, evaluate it and modify it to fit particular tasks.

The flexibility with which management support staff to experiment with change is a useful analogy that HSE should consider in its engagement with NGOs. Overly prescriptive approaches to change are unlikely to impact on the organisational culture of agencies and generate lasting change. The recommendations of the Value for Money and Policy Review of Disability Services may be seen as

applying a prescriptive relationship between HSE and NGOs. Service Level Arrangements will specify measurable performance indicators with ongoing monitoring and compliance reviews. This approach reflects a 'new public management' (NPM) approach to public services popularised by wealthier economies espousing competitive tendering, adherence to key performance indicators and sanctions for non-compliance. It is questionable if this approach can deliver the type of inherent change required within the core ethos of some disability organisations.

> Now tendering is theoretically fine but I worked with a guy who was involved in a service in Australia and had something similar to the tendering and what actually happens is that, the company might change, the name of the company might change but the people delivering the service would remain the same.

A more appropriate governance model may be the experimentalist approach (Marsh & Spies-Butcher, 2009; Power & Kenny, 2011). This approach acknowledges the need for services to find local solutions to complex frontline issues which arise. Implementation and monitoring are not pitted against each other in a prescribed way, but rather work in tandem. Actions are implemented, regularly reviewed and undergo continual iteration (Sabel & Zeitlin 2012).

Given the level of confusion and potential resistance to the proposed policy reforms HSE's relationship with NGOs is a key catalyst for change. A partnership approach with flexibility for agencies to experiment may be a more suitable vehicle for sustainable change than more traditional and prescriptive approaches.

9.4 HSE Commissioners: Trends by Region

Stark differences were apparent in the discourse from commissioners working within the two regions. Throughout the interviews with representatives from Region 2 the reasons for their greater progress towards deinstitutionalisation became apparent. Over thirty years ago, one individual was identified as a champion of community-based services and held a position of authority that enabled this vision to become a reality. An evaluation of services was conducted in the region recommending a transfer of services to the community. A full thirteen years later a project team was assembled to begin the closure of the larger settings. Within the subsequent years a 'no new admissions' policy was introduced. The timing of this policy coincided with a period of economic boom in Ireland which provided access to capital grants for properties. Other challenges presented themselves, notably staff and unions:

> Because it rolls out after that, you know, and the blockages were unions. And the staff issues. They were the only blockages I was aware of until, well money was fine

The momentum for community living sustained over the years infusing the region with an ethos where community living is the expectation for people with intellectual disability. Five years ago plans to develop a cluster setting were refused by HSE. Throughout the period mainstream housing has become the norm, a likely explanation for the strong relationship observed between senior agency personnel and mainstream housing bodies in this region. When asked about the challenges of accessing mainstream housing one commissioner reported:

> We have that already. Everybody has their name on the housing list that requires it.

This strategy can be contrasted with the continuing struggles faced by commissioners in Region 1 who, in considerably more austere times, are attempting to build a relationship with mainstream housing providers:

> You go to the housing authority and they say "we don't have it" and we're saying but you must have it. You must have social housing for someone who wants to live independently?

The momentum for more personalised services gathers in Region 2. Efforts are now focusing on accessing private tenancies rather than reliance on social housing:

> When people present, we can't give them residential housing. What we would do though is we would support people in private rentals.

Commissioners within Region 2 are fast approaching the closure of all congregated settings. They are now turning attention to the provision of more personalised supports for people currently living in the community.

> And then my view is that at least that's done so if we look at it as a continuum we can say that that part of it is now gone, so the community house model, where you've 4 and 5 and 6 people living, supported by nurses and care staff, whatever, that we need to now focus here and to progress and move people along.

The progress towards community living illustrates the impact of one individual in a position of authority. Notwithstanding this achievement, the timing of an economic boom during the transfer of services to the community was fortuitous.

Summary findings from Results: The Perspective of HSE Commissioners

• HSE Commissioners described a challenging and under-resourced working environment. The expectation is that HSE may become a commissioning only body.

• Poor communication within and beyond HSE has caused a level of confusion and anxiety about the proposed reconfiguration of services. HSE take responsibility for communication within HSE but proposed NGOs and advocacy organisations take responsibility to inform families and other stakeholders.

• Commissioners understood that there was no standardised implementation plan to implement the recommendations of the congregated settings review. Implementation was thought to be local and evolve with time. Some commissioners called for more prescriptive measures such as key performance indicators to ensure against drift.

• Leadership within HSE is largely perceived as absent. Commissioners were of mixed opinion however as to just how prescriptive HSE should be in driving change.

• Commissioners were generally critical of the level of control they had to enforce reform; either through rewarding good practice or sanctioning poor performance.

• Staffing is a key barrier to reform. The moratorium on recruitment and representation of psychiatric nursing within the discipline needs to be addressed. Exposure to demonstrations of good practice is also required.

• Commissioners are hampered by a lack of good quality data from NGOs. Adherence to Service Level Arrangements and the development of a national resource allocation system will provide valuable data.

• Commissioners may find that a less prescriptive, albeit well monitored approach to governance is more likely to realise sustainable reform. Experimental governance models are more likely to encourage staff to engage with change than new public management approaches.

• A clear regional difference was observed in the commentary of commissioners from both regions. Commissioners in Region 2 outlined a history of developments in their region commenced by one champion of community-based services. What followed was a programme of reform including 'no new admissions' policies to congregated settings, no cluster developments and the use of personal tenancies to support individuals in their own homes. These changes were largely instigated at a time of economic boom.

10. Results: Regional and National Perspectives

Seventeen regional and national experts participated in interviews for *Moving Ahead*. Interviewees represented a variety of roles and responsibilities within the disability sector including commissioning, regulation, policy, advocacy, and service provision. Also represented were individuals working within mainstream services that are likely to play a greater role in supporting people with intellectual disability living in local communities. This group included people working within employment, health, and housing services. Findings from these interviews are presented within the context of policy implementation and refer to national level issues to avoid duplication with previous sections. Issues are presented at the level of the individual, family, agencies, commissioners and mainstream services.

10.1 ISSUES FOR PEOPLE WITH INTELLECTUAL DISABILITY

Interviewees expressed their concern that some agencies prioritised moves from congregated settings without appropriate consultation with individuals with intellectual disability. Several interviewees with direct experience felt there was a general inaccurate perception that people with intellectual disabilities lacked capacity to engage in decisions about living arrangements. For these experts capacity was not at issue, rather the process of engagement was inaccessible for people with disabilities: individuals were simply not empowered to participate.

These challenges were perceived to exist, and perhaps causally so, within the absence of appropriate advocacy services in Ireland. Many interviewees were highly critical that the voice of people with intellectual disabilities was largely silent at agency level, local level and nationally. Most self-advocacy groups were located within disability agencies which by definition could not provide independent advocacy. Two independent advocacy services had established in 2011, the National Advocacy Service and the National Platform of Self Advocates. While these services were welcomed by experts, they were also deemed to be highly under-developed.

> Quite often what's happened is decisions are being made around moving people out and the person is not central to that process, you know, which obviously flies in the fact of congregated settings [*report*].

An issue garnering mixed response from experts was the particular circumstances of older persons with intellectual disability who lived in congregated settings for most of their adult lives. Some experts were of the opinion this cohort of people should be prioritised to move to the community to ensure they could experience community living within their lifetime. Others expressed reservations suggesting that this group of individuals should be facilitated to live out their lives in familiar settings.

In combination, these issues are a salutary reminder that the drive towards more personalised and independent services has occurred largely in the absence of meaningful consultation with people with intellectual disabilities. Moreover, current advocacy services fall well short of what is required to empower individuals to exercise any control in their choice of living arrangement.

10.2 ISSUES FOR FAMILIES

National and regional experts cited many family concerns primarily about potential losses of services which have been reported elsewhere in this report. These concerns will not be duplicated here. An overarching theme bridging much of this commentary was a perceived reneging of the contract

between agencies and families. Interviewees acknowledged that, most especially for older families, the decision to place a family member in the care of professionals was one of the most difficult decisions they ever faced. These families were now being informed that the support they received over many years was poor practice.

> I think they are also afraid of facing 'What did I do to my child?' And so if you're told that your child had to go away and you got the best place for them and you could only go visit them at visiting hours in the parlour or whatever. And then you're told, 'Well we did it all wrong'

Families were expected to put their faith in a new model of support advocated by the same professionals who previously advocated congregated supports. Moreover families were asked for blind faith given the lack of exemplars of newer models of support.

> Nobody has actually provided a vision of what the world looks like in the future […] nobody has offered that picture and at least if you could begin to offer that picture to people, then they could begin to visualise it. And then they could start to get comfortable with the idea of it. But in the absence of a picture, there's just uncertainty.

Similarly to people with intellectual disability, families have been largely excluded from the development of disability policy. A number of experts commented that their representation on agency and HSE fora was tokenistic. Advocacy agencies with a remit to support families also came under criticism for failing to inform families of recent policy developments.

Considerable efforts are now required to redress this imbalance and empower these stakeholders to become equal partners in the decision making process.

10.3 ISSUES FOR SERVICE DELIVERY

Interviewees acknowledged the impact of the economic recession on the allocation of resources throughout disability services. Staff shortages were deemed to contribute to a return to group-based support and risk aversive cultures. Some national and regional experts were critical that front line services were impacted in this way while the terms and conditions of existing staff remained intact. These interviewees argued that the disability sector was very significantly funded yet chose to deliver a 'less than optimal service'.

At issue was the fact that staff salaries were beyond the control of individual agencies due to national pay agreements. There was some consensus that these pay agreements were unsustainable in the long term and that international trends towards de-professionalisation of the sector was inevitable. Some interviewees proposed that agencies could reduce costs and deliver quality services through changes in rostering. These changes were thought to be unpopular with staff but could deliver efficiencies while maintaining quality.

> [*Agencies*], were saying, 'You've cut our budget by 3% - we've no money.' Actually by tackling the rosters they found money. There were places that looked at whether you could put in technology. Would people need overnight care – they didn't need overnight care but the staff wanted [*it*].

Industrial relation challenges were predicted, notably with nursing staff. Professional nursing bodies were known to be lobbying for the retention of nurses within intellectual disability services.

Some experts were skeptical that disability agencies would be sufficiently motivated to embrace the proposed level of policy reform. These interviewees described a conflict of interest where agencies

which had amassed considerable property portfolios were unlikely to willingly divest themselves of these assets. HSE commissioners had also mentioned a potential conflict of interest here accusing some agencies of engaging in 'empire building'. For some experts the practice of agencies establishing their own housing associations was seen as a breach of the spirit of new policies which called for the separation of housing and social care. The practices were described as reflecting organisational cultures that were risk aversive and paternalistic and would be slow to change.

10.4 ISSUES FOR COMMISSIONERS

Like other stakeholder groups, these interviewees expected that HSE would become a commissioning only body in time, with competitive tendering becoming the dominant commissioning model. The general consensus by interviewees was that competitive tendering favoured minimal standards at lowest cost. Competitive tendering was also thought to damage the commissioner provider relationship.

At the time of these interviews HIQA, the statutory body responsible for standards and inspection of healthcare services, was about to commence inspections of residential services for people with disabilities. The introduction of these inspections was broadly welcomed as an instrument to ensure quality services were delivered.

There was confusion however as to whether HIQA's remit to inspect 'designated centres' would or should extend to individuals living in mainstream housing. For some interviewees the notion that inspectors would visit a person's own home was unacceptable. Others were concerned that on the one hand policies were promoting more individualised and independent supports, while on the other these living arrangements may fall outside any protection afforded by recent regulation.

> No, nobody will be picking up on them, no no no. So what will have happened is the umbrella of regulation, which is intended to protect people and ensure people are receiving safe and appropriate services, people will have moved out from under the umbrella.

Challenges in commissioning were acknowledged by interviewees, in particular the lack of authority HSE commissioners had to reward quality services or sanction poor practice. A number of experts commented on practices in other jurisdictions where commissioners instructed agencies to incrementally allocate greater proportions of their funding to new service delivery. Far from delivering such proactive strategies, HSE were accused of inertia.

Individualised budgets, based on independent assessments of need, were identified as a key driver of reform that would radically alter the commissioning landscape; individuals would become commissioners of their own supports. Interviewees expressed frustration at the slow progress towards the introduction of resource allocation models that would facilitate individual budgets:

> While we have the reports and everything else like there isn't a clear structure how to go about getting individualised funding. I suppose what we would like to see is clear direction from the Department of Health saying , 'this is how you go about doing individualised funding' and pieces in place, you know, whether it's brokerage or whether it's micro boards or whatever it is […] until we have that in place it's always going to be a struggle.

A related stumbling block was the challenge of developing brokerage to guide individuals on what services they could commission using their individualised budget. Clearly a conflict of interest arises if agencies delivering services are also providing guidance to individuals on which services they may

purchase. Interviewees expressed their concerns that no progress had been made in the development of individual brokerage.

Experts acknowledged that demonstration projects were a key vehicle from which commissioners could trial new services and showcase their effectiveness. A general concern was the governance of some of demonstration projects. Interviewees argued that some projects may be perceived as addressing current gaps in service provision rather than pioneering new service provision. Also, more confidence would be instilled in projects if their sustainability and generalization into mainstream provision were demonstrated.

10.5 ISSUES FOR MAINSTREAM SERVICES

Experts from mainstream services including employment, health, and housing were interviewed to elicit their views on the current capacity of mainstream services to support people with intellectual disability. Interviewees noted their growing engagement with people with intellectual disabilities but some felt their professions in general may be unaware of the trends towards mainstream provision. Unlike other marginalised groups, people with disabilities were deemed to have significant support from disability services and many interviewees proposed that this expertise would be required in tandem with mainstream providers to deliver optimal services.

Interviewees working in employment services were asked about their role supporting individuals with intellectual disability access employment within local communities. These services were community-based providing specific supports to those traditionally excluded from the workforce. To date, support was largely provided to individuals with disabilities without the intervention of disability service providers. People were typically self-referring or presenting with the support of a family member.

Feedback from those in employment services was that individuals with intellectual disability were not presenting 'job ready'. Sourcing jobs in recessionary times was challenging for all job-seekers but interviewees reported finding it especially difficult for people with intellectual disabilities. More support was needed in general areas such as time-keeping; without these basic skills people were unlikely to secure or maintain employment. The challenge for employment agencies was that their large caseloads did not permit the individual attention they deemed necessary to prepare people with intellectual disability to enter the workforce. Assistance from disability agencies could provide the additional and expert support needed, however engagement to date between employment and disability services was typically poor.

> [*Support staff from disability agencies*] that would be assigned, very little training, no real sort of experience of the job in hand which is supporting a person in the workplace and helping to integrate, helping with induction, helping to break down barriers with co-workers and, you know merge all that, and they've come from a completely different background […] one guy we had one time, he sat out in the car while the person was in doing the jobs and when we questioned him, he said, 'No no that's not my role. I only said I'd bring them here, and sit outside you know.'

An additional barrier to employment mentioned by some interviewees was the 'benefits trap'. Many adults with intellectual disability are in receipt of disability allowance, a means-tested benefit issued by the Department of Social Protection. Individuals may, with permission from the Department, engage in rehabilitative work to a maximum of €120 per week while retaining their disability allowance. Earnings over this limit result in deductions to disability allowance. For some individuals the loss of a secure income stream in favour of a potentially short-term job opportunity was a risk too far.

In general, those working in employment services felt unprepared for a potential increase in the numbers of people with intellectual disability seeking their services. Their experiences to date were challenging and they questioned whether they had the specialist expertise necessary to accommodate people who had higher support needs. Interviewees welcomed the possibility of greater collaboration between mainstream and disability services, albeit feeling that negotiations between the two parties were long overdue.

Use of mainstream health services was examined in relation to primary care, specifically general practice. A similar concern to that of the employment specialists was levied here; general practitioners were deemed under-resourced and ill-equipped to support the health needs of people with intellectual disability. Primary care was described as being under significant pressure throughout the recession with general practitioners being asked to produce more with less. The health needs of individuals with intellectual disability were deemed to be well supported by disability agencies at a level that was not deemed possible for primary care. Without additional resources general practitioners were thought to have neither the expertise nor time required to optimally support people with intellectual disability. Interviewees were also critical that the proposed transfer of responsibility for the heath-care needs of people with intellectual disability had occurred in the absence of any negotiation with medical associations representing the profession. Considerably more discussion was deemed necessary before any transfer of healthcare responsibility to primary care.

Accessing mainstream housing was distinguished from accessing employment and health services on the basis a formal strategy had issued, the *National Housing Strategy for People with a Disability.* At the time of interview, implementation efforts were underway, notably the development of national protocols among key stakeholders including the Department of the Environment, Community & Local Government, the Department of Health, local authorities, the HSE and the Irish Council for Social Housing.

Due to a significant housing shortage the strategy's chosen model for the delivery of housing services was social leasing delivered through housing associations. Housing associations, some of which were established by disability providers, provide long term leasing options for vulnerable groups, typically for 15-20 years in duration. Tenancies are provided and payments include contributions both from the local authority and from the tenant to meet the market rental value of the property.

Some challenges were foreseen during the implementation of the strategy. Questions were raised as to whether some housing associations had sufficient expertise in housing to deliver social leasing. Some housing associations had a history of failing to provide for the social needs of tenants, leaving local authorities, and their over-stretched welfare officers, providing both housing and social supports. Questions were also raised about the level of expertise within disability agencies that had recently established housing associations.

Accessing suitable properties was a significant barrier. Housing in the economic recession was generally in short supply, but a significant number of empty and in many cases unfinished properties were now in the control of the State. These properties, colloquially known as NAMA properties, were identified as a possible source of housing. The advantage of these properties was that they could be suitably adapted for people with disabilities; the disadvantage was that the location of some was undesirable.

Attempts to identify the population of people with disabilities in need of housing were hampered by a lack of poor data. Housing needs assessments were conducted on a three yearly basis to identify those on the waiting list for social housing; this assessment was highly problematic for people with intellectual disability. Essentially, individuals are surveyed and asked to confirm that they are still in need of social housing. In the event of a non-response, individuals are removed from the housing list.

This system was deemed to discriminate against people with intellectual disability who may, for a variety of reasons, fail to respond to the survey. The National Federation of Voluntary Bodies, an umbrella organisation for non-statutory agencies, was providing assistance in creating awareness of the survey among its membership.

Other practices were also identified which were thought to discriminate against people with intellectual disability. Some local authorities deemed people with disabilities living in congregated settings to be adequately housed. Some individuals were deemed to be in receipt of double payments if they were receiving services from disability organisations while also seeking rent supplement. Applications for housing support typically require documentation such as passports, bank accounts and utility bills, documentation which people in congregated settings were unlikely to possess. These issues were being addressed in the forthcoming protocols.

The allocation of social housing differs nationwide as a reserved function of local counsellors. The Government may issue guidance but is not involved in allocation. Some local authorities allocate social housing on the basis 'time on waiting list'; those who are longest are offered housing. Others use points systems depending on individual circumstances such over-crowding, or number of children. In some local authorities 'time on waiting list' is combined with a prioritisation of whether individuals are deemed ordinary cases, homeless cases or welfare cases. People with disabilities are not prioritised on the housing waiting list by virtue of having a disability, but may be so if identified under the 'welfare' category. These variations in allocation meant that individuals with disabilities are more likely in some regions to access social housing that in others.

These housing challenges reflect the introductory phase of the implementation of the housing strategy. Unlike the other mainstream services reviewed here, the formal collaboration between Government departments representing health and environment, allied with HSE and other housing agents created an environment where responsibilities were discussed and collaborations agreed. It may be that a more formal approach to collaboration with other key mainstream providers may provide a useful forum to discuss and address arising challenges.

Summary findings from Results: The Perspective of Regional and National Experts

• Experts involved in commissioning, regulation, policy, advocacy, service provision and the provision of mainstream services identified issues impacting the national introduction of policy reform within the disability sector.

• Experts questioned whether appropriate consultation had been undertaken with people with intellectual disability about the proposed reconfiguration, and whether they were now appropriately empowered to exercise choice in their new living arrangements. Advocacy was considered extremely poor at agency, regional and national level.

• Families too were deemed in need of greater advocacy. Their confidence in services who once promoted institutional care was now being tested.

• Experts were critical of reductions to front line services while terms and conditions of staff were protected. Salaries were deemed unsustainable and de-professionalisation was deemed likely for parts of the disability field. Experts also questioned whether a conflict of interest existed for agencies divesting responsibility to those they support while amassing property portfolios.

• If international trends are followed competitive tendering may become part of the commissioning landscape. This type of commissioning was deemed too blunt an instrument to purchase quality services.

• Experts were unclear whether HIQA would conduct inspections of more individualised living arrangements, notably tenancies. There was mixed opinion as whether individuals' own homes should be included within the regulatory framework.

• Individualised budgets were endorsed by all interviewees however the supporting infrastructure, resource allocation models and brokerage were deemed long overdue.

• Demonstration projects were deemed a useful vehicle to test new models of service. Greater clarity was called for on their governance and sustainability.

• Those working in employment services had limited experience supporting people with intellectual disability. In general, people with intellectual disability were not 'job ready' and required more resources than current services could provide. Interviewees called for collaboration between disability and employment services to meet need.

• Those working in primary care also felt they had insufficient resources to support individuals with intellectual disability who they deemed could more optimally be supported by disability agencies. Concern was expressed that no consultation had occurred with professional medical bodies.

• The existence of a formal housing strategy to support people with disabilities distinguished this mainstream service. While fledging in implementation the strategy promotes the use of social leasing via housing associations.

• Challenges to the use of mainstream social housing tenancies included insufficient appropriate housing, lack of data on those seeking housing, perception than some individuals are doubly funded from different funding schemes, and required documentation for people in congregated settings.

• While differences were apparent in the criteria for allocating houses used by different local authorities, the housing strategy protocol was clear that those in congregated settings were not 'adequately housed'.

11. Conclusions and Required Actions

Deinstitutionalisation is the single most significant policy development for people with intellectual disability since the post-war period. The transfer of large numbers of individuals from segregated settings to local communities is evidenced to result in considerable quality of life gains. For individuals with intellectual disability in Ireland, the following decade is likely to realise the closure of all congregated settings and the development of more personalised, community-based services. This programme of reform is driven by a vast array of disability policy over the preceding twenty years. In total, 16 policy reports have issued; six since 2011.

Despite this momentum, the Department of Health acknowledge implementation has occurred at the pace of 'slow and tentative drift'. A contributing factor to this drift is the status of non-statutory service providers in Ireland. The lack of accountability of these providers to the state commissioning body, HSE, has been the subject of repeated criticism. Service Level Agreements (SLAs) between agencies and commissioners have been identified as having significant shortcomings, notably a lack of detail on the precise units of service delivery for the population receiving services. Moreover, situations have been identified where services were operating in the absence of SLAs. These criticisms illustrate the unparalleled role of the NGO sector in the delivery of disability services in Ireland. Their level of autonomy in service delivery has led critics to comment that service delivery may more likely reflect agencies' own organisational mission and individual personalities than the needs of those they support. Moreover, the involvement of people with intellectual disability and their families as key stakeholders is almost completely absent.

Proponents argue it is simply not feasible to leave the process of deinstitutionalisation within the remit of those delivering services. Planning must be led at regional or national level to drive the scale of reform required with commitments from all key stakeholders including government agencies, commissioners, and disability organisations. Given the significant influence of the disability organisations themselves in implementing reform, it is surprising that their specific contribution to deinstitutionalisation is rarely researched. Research within the generic field of organisational dynamics identifies how organisations typically respond to the pressures of policies seeking radical reform. Leadership, clarity from management, and attitude to change are key mediating factors. Difficulties in implementation may occur where an organisation's own values and practices do not align with proposed reforms.

Change should be introduced incrementally supported by training, clearly articulated goals, and transferable knowledge. New practices are more likely to be adopted if staff are enabled to experiment with them, evaluate them and modify them to fit local purposes. More often change is introduced in a hierarchical fashion, a process that is likely to alienate and cause resistance. This pattern is also observed at the commissioning level where commissioners call for detailed and specific performance indicators, ongoing monitoring and compliance reviews in policy implementation. This approach to governance, termed New Public Management (NPM), may similarly alienate those delivering services and cause resistance. A more appropriate governance approach may be an experimentalist approach which acknowledges that broad services goals such as enhancing quality of life are not easily defined, measured and monitored. Moreover, these organisational goals may be influenced by local and regional issues which may be ignored within an NPM framework. In contrast, an experimentalist approach encourages the adaptation of policy to local needs and the use of

ongoing and iterative monitoring. This approach has been successfully applied in education and welfare settings but to date no evidence has been found of its application within disability services.

Regional variation in deinstitutionalisation has been observed at both international and national level. This variation may reflect the individual autonomy of disability agencies within these regions, however little research has been conducted to confirm this proposal. These differences have been observed in Ireland by Prof Roy McConkey and colleagues who inspected patterns of living arrangements for individuals with intellectual disability from 1999 to 2009 in Ireland. Their findings illustrated substantial progress in deinstitutionalisation nationally throughout this period, but also revealed major variation at regional level. The factors underlying these regional differences are not well understood. This issue was the substantive research question for *Moving Ahead.*

A robust methodology including both qualitative and quantitative methods was used to explore the research questions. Using national level data two regions in Ireland were selected to represent areas where progress to deinstitutionalisation differed markedly. Within each region four service providers participated in *Moving Ahead*; in each region a HSE service (providing both institutional and community-based services), a large NGO (providing campus-based and community-based services), a small NGO (providing only community-based services) and a supplemental agency. In total, these eight organisations accounted for 65% of all services delivered within these regions. These agencies were used as recruiters for people with intellectual disability, family members, direct support staff, clinicians and senior agency personnel. There is an inherent bias in recruiting individuals via the service which provides their support. To minimise this bias the research team provided criteria for the recruitment of these stakeholders. The criteria for invitations to family members, for example, were that this group should comprise parents, sibling, other relatives, show representation across age, and representation across their family member's living arrangement. The use of these criteria is considered good practice and aims to ensure that fair representation is observed.

In total 354 individuals participated in *Moving Ahead*. This figure included not only those receiving or delivering services within the two regions, but also HSE Commissioners within the regions and a number of experts at regional and national level whose input aimed to acknowledge the broader context beyond the participating agencies.

11.2 ARCHIVAL DATA

HSE National Service Plans: incongruence of policy and practice

Archival data was examined from two sources; HSE National Service Plans and the National Intellectual Disability Database (NIDD). These data were used to outline the national and regional context within which the eight participating disability agencies delivered their services.

The HSE National Service Plans provide annual information on the proposed services HSE aim to deliver within a given year. They do not include information on whether deliverables from the preceding year were met; failure to disclose this information may be deemed to represent a lack of accountability within HSE. The plans do however provide a useful framework to examine the priorities of service delivery and the impact of external influences, notably finance, on the delivery of these services.

The review of HSE National Service Plans spanned from 2005 to 2012, a period of extraordinary financial restriction within the Irish State. At the beginning of this period plans were characterised by investment in service delivery, albeit increases in service 'places' that may be considered somewhat traditional in light of subsequent policies advocating the development of highly individualised services.

Investment was also aligned towards efforts to support individuals navigate the services landscape through improved pathways to care and enhanced advocacy services. The National Disability Strategy was launched in 2004 providing a suite of legislation, interdepartmental responsibilities and a ring-fenced Multi-Annual Investment Programme (MAIP) of €900 million to enhance service delivery. While MAIP was unable to reach its full commitments due to the economic crash, there is evidence of substantial increases in staff numbers funded through this initiative. Legislative reform included the EPSEN Act, Disability Act and Citizens Information Act. Developments for major reform were also in train including reviews of children's services, notably their access to assessments of need, and adult day and residential services. These reviews were completed with the period of review (2005-2012).

By 2008 the landscape of investment, legislative and service delivery reform was altered significantly in light of the national economic crisis. The subsequent years introduced a series of financial cuts to disability services to a cumulative total of 10.5% by 2012. A moratorium on staff recruitment and national pay agreements meant that these cuts were requested from non-pay budgets, essentially back-room costs. Other data from *Moving Ahead* would suggest that these cuts impacted on front line services with a return to group-based activities and reductions in social engagement despite the introduction of policies espousing the development of highly individualised, community-based supports. The financial crisis can be identified as a contributor to the failure of practice to reflect policy reform.

The National Service Plans also identify capital investment over this period. Projects in 2009 included an eight bedded 'residential facility', a 60 bed bungalow street-scape, and a 30 bedded residential unit. These projects precede the 2011 publication of the HSE review of congregated settings advocating the closure of all residential services providing for ten or more individuals with disabilities. It may argued however that sufficient evidence was available at this time suggesting a policy push towards smaller, community-based living options. Since 2007, Ireland had signed the *UN Convention on the Rights of People with Disabilities* which protects the rights of people with disabilities to live in the community. These capital investments indicate that notwithstanding the impact of the financial crisis, high level decision-making was also a contributor to the failure of practice to reflect policy reform.

By the end of the review period in 2012 plans called for new models of service to be introduced *'in a manner which is efficient and cost-effective'*. HSE's combination of policy reform and cost savings may have sent a mixed message to stakeholders whereby the two issues become causally linked; the need for cost savings becoming a driver of proposed reforms. Targets for introducing a resource allocation model based on individualised budgets simultaneously with a call for financial cuts across the spectrum of service delivery may present the optics that individuals will receive less funding in a personalised budget than through block funding mechanisms. Given the poor communication of disability policy evidenced elsewhere in *Moving Ahead*, the message that more individualised services are advocated on the basis of quality may be overshadowed by the message that cost efficiencies are required throughout the sector. These mixed messages contribute to stakeholders' skepticism that a desire to save money is the main driver of reform.

The review of HSE National Service Plans is helpful in illustrating the influence of the broader financial environment on the implementation of policy. The combination of financial cuts impacting on the personalisation of services and continued investment in congregated settings would question HSE's commitment to policy reform. These inconsistencies and poor communication of policy are unlikely to win over those who may speculate that policy reform is driven more by finance than by the needs of people with intellectual disability.

Disability trends with participating regions

Throughout this period of reform the two regions participating in *Moving Ahead* reported sharp differences in their progress towards deinstitutionalisation. Prof McConkey and colleagues presented these differences from 1999 through to 2009 using data from the National Intellectual Disability Database (NIDD). Data from NIDD were examined again in greater detail in *Moving Ahead* to see if the disparity remained and whether any conclusions could be drawn on where precisely the disparity lay.

Data from 2011, at the start of *Moving Ahead,* indicated that the disparity remained and was largely due to the provision of seven day residential supports. Region 1, which has made less progress to deinstitutionalisation, differs from Region 2 by providing residential centres as its most dominant form of living arrangement. Region 1 also supports younger and more able individuals in these settings, and reports considerably less movement of people to community settings in the five years preceding *Moving Ahead* when compared with Region 2. These differences exist despite the highly similar demographic profile of the people supported in the two regions. Factors other than the support needs of individuals seem to be driving the disparity in service provision.

Collectively, these data indicate that either there is little pressure being put to bear on those delivering services in Region 1 to adhere to policy reform, or if such pressure is being applied, it is having little effect on the living arrangements of individuals living in this region.

11.3 MOVING AHEAD SURVEY OF PEOPLE WITH INTELLECTUAL DISABILITY

Two broad research questions were posed in *Moving Ahead*. A survey of individuals with intellectual disability using services within the two regions was used to address one of these research questions:

For people with intellectual disabilities in the two regions, how do their characteristics and quality outcomes differ if they live in dispersed community-based settings compared to congregated settings?

This research question was broken-down into four sub-questions:
  i. *How do their demographics and support needs differ?*
  ii. *How do their health status and access to health services differ?*
  iii. *How do their quality outcomes differ (e.g. exercising choice, community engagement, quality of life)?*
  iv. *How do the physical staffing practices and staffing levels differ and can indicative costs be determined using staffing levels?*

In total, 136 individuals with intellectual disability participated in the *Moving Ahead* survey with the support of their keyworker or by proxy. The number is smaller than envisaged with a response rate of 59.4%. Some parts of the survey were poorly completed restricting the level of statistical analysis. Mindful of these caveats the survey provides valuable information on the outcomes for individuals in the two regions.

An unexpected issue arose in survey responses relating to the definitions employed for various living arrangements. The issue arose because community-based and congregated living arrangements are not, by definition, mutually exclusive. For many participants, their location within the community was deemed to classify them availing of community-based living arrangements. In fact, further information revealed that for some individuals their location was community-based but their living arrangement

could be deemed congregated as per HSE's 2011 review of congregated settings. HSE defined larger congregated settings as dwellings with ten or more persons or dwellings which are campus-based. HSE recommended that individuals living in these settings move to dwellings with no more than four persons scattered through residential neighbourhoods; by implication settings for more than four people or in clusters in the community will be deemed congregated.

Given the lack of finality on these recommendations (HSE has yet to agree a date for the cessation of admissions to congregated settings) it may be reasonable to propose that provider agencies may prioritise the movement of people to dispersed housing in the community to settings of nine or less. Such a definition would mean that community group homes which currently support approximately six individuals, and which are the most dominant form of residential support nationwide, would not meet the criterion of a congregated setting. In contrast, the issue of clusters of housing within the community is a criterion which should be considered at the current time for individuals moving to the community. Decanting institutions to clusters in the community is a strategy that is contrary to the notion of dispersed community living. For these reasons the *Moving Ahead* survey described community living as dispersed dwellings located in the community supporting less than ten people.

This definitional issue has important implications for monitoring the progress of deinstitutionalisation in Ireland. Current tendencies to classify individuals located in the community as community-based and all others as congregated are likely to underestimate the level of reform required. Data is needed not only on the precise numbers of individuals living in each dwelling, but also on the presence of other staffed properties within the area. This level of data is a necessity to monitor the successful implementation of recent disability policy.

Using the *Moving Ahead* criteria, dispersed community living was more common among sample participants living in Region 2 than those living in Region 1, reflecting a similar pattern to that observed for all persons in these regions as identified by the National Intellectual Disability Database (NIDD).

How do their demographics and support needs differ?

The data revealed that the demographics of age and gender did differ according to the region where individuals lived; those in Region 1 were more likely to be younger and male. They were also more likely to be reported by staff as engaging in behaviours that challenge. These demographics did not differ according to whether individuals lived in congregated or dispersed living arrangements. Support needs revealed the reverse pattern; level of ability and support needs did not differ depending on which region people lived in, but did by their type of living arrangement. People living in congregated settings reported lower level of ability and higher support needs than those living in community housing.

The differences suggest this sample is slightly skewed from the full population of people receiving supports in these regions as documented by NIDD where gender, age and support needs did not differ by region. This skewing towards younger men may be influential in the staff ratings of greater occurrences of behaviours that challenge. Of particular interest is the finding that support needs do not differ by region, but do differ by living arrangement. As with data from NIDD, the survey data suggest that factors other than the support needs of individuals seem to be driving the disparity in service provision.

How do their health status and access to health services differ?

Health status and access to health services tended not to differ by region or by living arrangement. The vast majority of people reported very good health; previous research suggests some of this positivity may reflect an acquiescence bias. The majority of people also reported co-morbid health conditions, of which epilepsy, speech difficulties and mental health were most common. Engagement in exercise and prescription rates for epilepsy and anti-psychotic medication were similar for people living in the two different regions, and for people living in the two different types of living arrangements. People living in congregated living arrangements were marginally more likely than those living in dispersed housing to use acute health services and services that were provided by disability agencies; given the high numbers of individuals reporting co-morbid conditions across all living arrangements, this trend may reflect the more medicalised environment traditionally associated with congregated living arrangements. In general, health status and access to health services did not differ substantially depending on which region a person lived in or whether they lived in congregated or dispersed community housing.

How do their quality outcomes differ (e.g. exercising choice, community engagement, quality of life)?

Life satisfaction, levels of contact with family and friends and access to independent advocacy did not differ depending on which region people lived in or whether they lived in congregated or dispersed housing. People living in dispersed housing did enjoy some quality outcomes not shared by their peers in congregated living arrangements; they were more likely to engage in community activities and had more opportunities to exercise choice. These findings suggest that a person's living arrangement has greater impact on their quality outcomes than the region they live in; dispersed community housing afforded greater quality outcomes.

How do the physical staffing practices and staffing levels differ and can indicative costs be determined using staffing levels?

This research question cannot be addressed by the data gathered in *Moving Ahead*; the level of missing data rendered the data unreliable. Given this level of missing data did not occur elsewhere in the survey, it is most probable that the information on staffing levels was simply unknown by the keyworkers who completed the survey. Questions were asked about the numbers of staff on a weekly shift and their grade of staff. This information, had it been completed, would then have been combined with salary costs to make a determination of indicative costs. While disappointing, the lack of data is itself informative as an indication of the lack of information direct support staff have about the day to day management of the dwellings where they provide support.

In combination, the survey findings suggest that an individual's level of ability and support needs are a distinguishing factor in their living arrangements; people with lower levels of ability and higher support needs are more likely to live in congregated settings. Moreover, it is a person's living arrangement rather than his/her support needs that seem to influence some outcomes including use of some medical services, engagement in the community and likelihood of exercising choice. The fact that regional factors do not seem to influence the majority of quality outcomes examined in this survey suggests that changes in living arrangements within these regions towards dispersed community housing will contribute to greater quality outcomes for these individuals.

The second research question posed in *Moving Ahead* was addressed through a suite of 22 focus groups and 24 interviews with key stakeholders. Focus groups were conducted with people with intellectual disability (42 participants attended five focus groups), family members (40 participants attended six focus groups), direct support staff and clinicians (94 individuals attended eleven focus groups). All of these focus groups were conducted in seven disability organisations, three of which were located in Region 1 (where progress to community services was slow) and four of which were located in Region 2 (where progress excelled).

Interviews were conducted with senior personnel; these participants were selected from the seven agencies above and an additional agency in Region 1(19 interviewees). Interviews were also conducted with HSE commissioners (six interviewees) and regional and national experts (17 interviewees). These stakeholders, representing eight organisations in the two regions, addressed the following research question:

What are the barriers and facilitators of deinstitutionalisation in Ireland, in two regions which differ in progress to community-based living for people with intellectual disabilities?

This research question was broken-down into five sub-questions:

     i.   *What are the views of major stakeholders of different living supports for people with intellectual disability?*
    ii.   *What do stakeholders cite as barriers and facilitators of community-based living?*
   iii.   *What role do organisational culture and ethos play in developing community-based living?*
   iv.   *What factors distinguish residential provision in the two regions?*
    v.   *What role do local and regional issues play in developing community-based living?*

What are the views of major stakeholders of different living supports for people with intellectual disability?

This question was addressed by asking stakeholders their views on four specific types of living arrangements: congregated settings, clustered arrangements, community group homes and independent living options.

Congregated settings were defined as settings where ten or more people live. The views of those with direct experience of either receiving or delivering supports in these settings seemed to be heavily influenced by their lived experience. Stakeholders currently receiving or delivering these services spoke of good physical care, and of benefits accruing to the spacious physical grounds that surround some of these settings. Critics, who were in the majority, spoke of their aversion to congregated settings arguing that they were incompatible with the provision person centred support. The use of congregated settings was associated with consideration of a person's support needs; some stakeholders arguing that congregated settings are the optimal living arrangement for people with high support needs.

Cluster living arrangements were defined as a specific type of congregated setting where dwellings were located on campus or in close proximity in the community. Clusters were popular with individuals with intellectual disability who welcomed the proximity of their friends, albeit they were

critical of the level of staff support for social activities. Families too were positive about clusters which they felt married opportunities for community engagement with high staffing support. Staff were more critical. Although some perceived clusters as appropriate for people with higher support needs, many described them as stigmatising 'mini-institutions' that afforded little opportunities for choice. Among more senior levels of staff opinion was mixed, but again mediated by personal experience. Agencies providing institutional care were far more tolerant of cluster developments. At regional level opinion was also divided. 'Modern' clusters were promoted in Region 1, while in contrast Region 2 introduced a policy five years ago that community houses would not be purchased in close proximity to avoid the possibility that clusters of housing would emerge.

Community group homes were defined as dispersed staffed housing supporting between three and six people. People with intellectual disability expressed highly favourable views of community group homes. People could exercise choice, receive good personalised supports and avail of community amenities. There was some criticism that personal privacy was limited. For family members, community group homes equate to community living. Continuity and appropriate staffing levels were identified as concerns, as was the possibility for tension between individuals house sharing. Staff were highly critical of community group homes which they deemed, like clusters, to be 'mini-institutions' affording poor levels of choice. Mirroring the views of family members, staff expressed particular concerns about the crude manner with which individuals may find themselves moving to a community group home with little or no consultation, and no knowledge of the other individuals who would now share their house. Community inclusion was deemed tokenistic and incongruous with personalised support. The comment by some senior agency personnel that community group homes were now closing at weekends due to funding cuts illustrated how easily these premises transform from a person's home to an agency's property.

Independent living was defined as exercising choice about where and with whom you live, ranging from minimal to fully staffed arrangements, alone or with others. This type of living arrangement was distinguished by generating most commentary as to what precisely it comprised. Generally, few stakeholders had direct experience of this type of living arrangement. Some people with intellectual disabilities who affiliated to independent living may arguably have also been described as living in community clusters. Irrespective of definitions, support as and when needed was a highly prized feature of this model for people with intellectual disability. The views of family members illustrate how lived experience and level of ability are key mediators in stakeholders' preferences for this model of support; independent living was, in principle, an admirable aspiration but not one that could be realised for their own family member given the person's support needs. Staff were less united in their response; again, lived experience played a mediating role. Staff in smaller community-based agencies with greater experience of independent living expressed concerns about whether individuals were being supported to become fully included in their communities. In contrast staff working in HSE and larger organisations were more likely to express their concerns that agencies were moving people to independent living too hastily and were failing to provide sufficient levels of support.

Senior agency personnel were less cautious in their perception of independent living and advocated a more informal approach to determining the suitability of individuals who may wish to trial this type of living arrangement. Some agencies specifically targeted individuals who expressed dissatisfaction or were experiencing difficulties with other types of living arrangements. This stakeholder group, as with many others, also discussed what exactly independent living comprised. Senior agency personnel in Region 1 referred to a hybrid model of 'supported independent living' which referred to floating supports in clustered settings. These arrangements did not meet the working definition of independent living for Region 2 where independent living referred to dispersed housing. Region 2 prioritised independent living options when referring individuals to new types of living arrangements. Senior

agency personnel were generally of the opinion that families and staff would be highly resistant to independent living.

Some clear trends emerged in stakeholders' views of these different types of living arrangement. Stakeholders' preferences were largely influence by their own lived experience; stakeholders gravitated to living arrangements that were familiar. They were also influenced by stakeholders' perceptions of the impact of level of ability; some stakeholders felt that people with high support needs could not be supported in particular living arrangements.   These findings suggest that stakeholders need assistance to envisage different models of support, most especially how people with high support needs can be supported in personalised community-based living arrangements.

Stakeholders' preferences also provide an insight into the regional disparity towards deinstitutionalisation, notably in relation to the provision of cluster living arrangements and independent living. The perception of clusters differs markedly with less tolerance for this type of living arrangement in Region 2. In addition, Region 2 actively promotes independent living arrangements. These two models, clusters and independent living, sit either side of the community group home model, currently the most dominant form of living arrangement in Ireland. Developments in the two regions are distinguished by their choice of deviation from community group homes; Region 1 favouring the more traditional cluster style development, Region 2 favouring independent living options.

What do stakeholders cite as barriers and facilitators of community-based living?

Barriers and facilitators have been presented by each stakeholder group within their respective sections of the *Moving Ahead* report. This section presents a global review of these barriers and facilitators. As noted throughout the report, many barriers and facilitators are different sides of the same coin; the presence of a condition may act as a facilitator, its absence as a barrier, or vice versa. The section below outlines issues of influence for community-based living commenting on how each may be a facilitator, a barrier, or in some cases different sides of the same coin.

Challenges for those receiving services

The main issue raised by people with intellectual disability about community living was the need for good support. This was defined as support as needed to achieve the person's desired quality of life. Support came from many sources including staff, family, friends and natural supports in the wider community.   For some individuals support was provided in areas where it was neither needed nor wanted, while support in other areas, notably social aspects, was insufficient. Good support, meeting the individual needs of people with intellectual disability is a key facilitator to community living.

The discrepancy between supports provided and supports received reflect the general absence of the voice of people with intellectual disability in issues central to their quality of life. National advocacy fora were established in 2011, specifically the National Advocacy Service and the National Platform of Self Advocates. While welcomed, these services have little impact for many individuals. Self-advocacy groups, where they exist, are typically located within provider agencies placing their independence into question. The development of locally-based independent self-advocacy groups would facilitate people with intellectual disability to provide their perspective on the development of community services.

Concerns were expressed about the level of engagement people with intellectual disability had in their choice of living arrangement. This concern was manifest in stakeholders' criticisms of community group homes, their lack of representation at any decision making fora on their own living

arrangements, and within the context of crisis referrals which often occurred due to the death of the person's primary caregiver. In these situations individuals with disabilities may find themselves moving to a new living arrangement with minimal, if any, consultation. Some stakeholders argued that these situations arose because people with intellectual disability were too often presumed to lack capacity to participate in these decisions, while the more likely reason for their lack of engagement was that the decision making system was inaccessible for them. Greater efforts are required facilitate people with intellectual disability engage in decisions about their living arrangements. Greater efforts are also required to reduce crisis referrals; in particular planning is needed regarding support arrangements for individuals in the event of the death of a main caregiver.

Many stakeholders expressed concerns about the speed with which they observed people with intellectual disability moving to the community. While crisis referrals contribute to a rushed and unprepared process, stakeholders felt that many referrals were now characterised in this way to meet new policy directives. Concerns were expressed that moving people too quickly with ill-prepared staff could have devastating consequences for the individuals in question. Moves to the community are facilitated by sufficient time devoted to planning, involvement of support staff who know the person well, and comprehensive transfer of information from the person's previous living arrangement.

High support need was raised by many stakeholders as a barrier to community living; people with high support needs were less likely to be offered opportunities for community living, and more likely to transfer to a congregated setting if difficulties arose. This group was typically defined as people with lower levels of ability, people with complex medical needs, and older people. People with intellectual disability spoke of how their own or their friends' failing health, often age-related, had resulted in a transfer to a congregated setting. Some stakeholders argued that people with high support needs cannot be appropriately supported in the community. Greater awareness is needed of how individuals with complex presentations are currently receiving good quality supports within the community.

Individuals who were older were a specific cause of concern for some stakeholders. Questions were raised as to whether a nursing home in the community differed from a congregated setting managed by a disability agency, and which of the two would provide optimal supports. Questions were also asked about whether it was fair or appropriate to move elderly people from institutions where they had lived most of their lives. These issues indicate that a lifespan approach to supporting individuals with intellectual disability is required.

Friendships and opportunities for social contact were highly prized by people with intellectual disability. Supports in establishing and maintaining friendships however were found wanting, not only by people with intellectual disability but also by other stakeholder groups. Greater emphasis is needed to support individuals in their friendships; this would also allay the concerns of some stakeholders that people with intellectual disability would be lonely if they lived in the community.

Greater emphasis is also needed to facilitate people with intellectual disability engage with natural supports within their community. Natural supports include neighbours and other people within local communities such as shop owners. Staff and senior personnel in disability agencies called for greater input to facilitate people to engage directly with natural supports. Social role valorisation was recommended as a facilitator. Social role valorisation promotes the concept that people with disabilities hold valued roles such as family members, friends, consumers and employees; roles which have traditionally become overshadowed by disability. These roles provide opportunities for people with intellectual disability to engage with natural supports in equitable and reciprocal relationships.

The central role of family in resisting or supporting a change in living arrangements was well articulated by people with intellectual disability; essentially, families either make or break any new developments. Many stakeholder groups involved in the delivery of services acknowledged that families were fearful equating any change in circumstances with a reduction of support. Some argued that families' suspicions reflected their perceptions that disability agencies were now reneging on their commitment to provide supports across the lifespan. These family concerns are a significant barrier for some individuals moving to community living.

The relationship between family members and direct support staff is crucial. Many enjoyed cooperative and supportive relationships. Some families however described poor relationships with direct support staff and described how they needed to be constantly vigilant to ensure quality was maintained. The opinion of many direct support staff was that families were more of a barrier than facilitator to any proposed change in living arrangements. This relationship between families and direct support staff requires attention by disability agencies; direct support staff represent the main interface with the agency for most families and any dissent in this relationship is likely to be a significant barrier to community living.

Another barrier for families in considering any proposed changes to a family member's support is poor communication. Many families felt excluded from decision making and were presented with a *fait accompli* regarding changes in support. Significant efforts are required to empower families to participate at decision making across multiple layers of service delivery, not only for their own family member but also within the wider context of disability policy. This level of engagement was absent for most families participating in *Moving Ahead*. The development of locally-based advocacy groups would facilitate opportunities for peer-to-peer support which in turn may alleviate some of the considerable concerns families have regarding any changes in service delivery.

Challenges for those delivering services in a changing policy landscape

A major barrier to community living for those delivering services is the poor communication of new policy. Below the level of senior management, knowledge of the proposed reforms for service delivery was minimal. People were aware of the basic concept that services were moving to the community but were unclear how this would be implemented, and how precisely it would impact on their jobs. Good practice would suggest that communication is an essential component of policy reform. It must be comprehensive in its reach to all stakeholders and should occur during set phases of implementation; at preparation, at introduction and ongoing throughout implementation. No evidence was found in *Moving Ahead* of a comprehensive communication strategy. Rather, examples were provided where staff signed off to indicate they had read policy documents. The absence of a communication strategy combined with tokenistic gestures is a key barrier to community living.

There is a lack of clarity as to who precisely is responsible for communicating new policy. Opinion was mixed as to whether HSE was responsible, or whether having devised the policies it was now up to those delivering services to communicate policies. Senior management in agencies certainly felt that they were left facing the ire of stakeholders who vehemently opposed the proposed reform. The lack of ownership of communicating policy is a barrier to effective communication and implementation.

Currently there is widespread distrust of the motivation behind these reforms. For many, the mixed messages of economic cuts and changes in service delivery have become causally linked. The possibility that quality of life may be enhanced by community living has been overshadowed by the certainty that funding, and by implication, support levels are reduced. There is also significant concern from some stakeholders that the closure of congregated settings will eliminate any 'back up

accommodation' for individuals who experience difficulties in the community. Greater efforts are needed to promote the benefits of community living and to disseminate good practice in supporting those who may experience difficulties.

Demonstration projects have been funded nationally to provide real examples where individuals with intellectual disability have moved to new models of community living. Moreover, they have been evaluated and report enhanced quality of life for participants. These projects provide valuable opportunities for people, families, direct support staff and managers to experiment with new models and adapt to local needs. Unfortunately, *Moving Ahead* found evidence that many stakeholders were largely unaware of the demonstration projects. It is essential that these stakeholders have the opportunity to observe first-hand the support arrangements of individuals trialling more personalised community-based living arrangements.

At more senior level, including commissioning, concerns were expressed about the financial sustainability of these demonstration projects when ring-fenced funding ceased. Many projects are co-funded by philanthropic bodies, notably an organisation called GENIO, with matched funding from disability agencies. Stakeholders questioned whether the projects could continue in the absence of GENIO funding. Concerns were also expressed as to whether this ring-fenced funding was diverted to fill service gaps rather than trial innovation. The perception that these projects may be unsustainable is a barrier to the future development. Relevant and accessible data on the findings of these evaluations needs a comprehensive reach, most especially to those who express concerns.

Similar concerns were expressed about opportunities to attend training sessions, seminars and conferences advocating community living. A number of stakeholders commented that typically these events were 'preaching to the converted'. Those who would benefit most, who are opposed to community living, are rarely in attendance. In particular, staff working in congregated settings described the prospect of working in the community as 'terrifying'. Nursing staff, highly represented in HSE services, were particularly anxious regarding their continuing role in intellectual disability services. These staff may wish to deploy elsewhere in the health service or to retrain in intellectual disability methods of support. If the latter, they need access to training. Finance was cited as a reason why direct support staff do not attend training and seminar events. In the absence of funding, disability agencies will need to consider creatively how to expose their staff to new methods of support. Exclusion from these events is a significant barrier to community living.

Organisational culture will be detailed in subsequent sections. Suffice to say here that *Moving Ahead* has demonstrated marked differences in organisational culture that mediate stakeholders' response to change. For some organisations, policy reform is a natural fit with their own organisational values. They espouse personalised, community-based supports for all individuals. Some may be deemed to act ahead of the policy curve. Other agencies work within the context of a culture of care, likely encouraged where staff have medical rather than social training. These agencies, and there staff, will need additional supports to make the paradigm shift to new policies. In the absence of targeted support to this group it is likely that support to people with intellectual disabilities will continue to be provided within a care framework regardless of location. Careful monitoring and inspection of community-based living arrangements are required to ensure that practices reflect person-centred approaches.

Organisational culture also raises the issue of 'empire building' cited by a number of senior stakeholders involved in the delivery and commissioning of services. These stakeholders felt that some organisations placed their own status above that of the people they support, espousing notions of personalised community supports while requesting HSE to find congregated places for individuals they deemed they could no longer support in the community. Others were less critical but felt that conflicts of interest exist for organisations who invest in their 'brand', most particularly through the

establishment of housing associations which would offer tenancies to the people they support. This practice was deemed to conflict with the spirit of policy reform calling for the separation of housing and support services. Some stakeholders also felt that the call for deprofessionalisation of staff may conflict with agencies seeking external quality accreditation. Again, careful monitoring and inspection is required to ensure that practices focus firmly on individuals and not organisations.

One the biggest barriers to community living is the current confusion regarding implementation of policy reforms to move people to the community. HSE commissioners participating in *Moving Ahead* understood that there is no standardised approach to implementation at national level; rather implementation will 'evolve' locally. Opinion was mixed on how prescriptive implementation should be; some advocated set deliverables monitored by key performance indicators, others advocated giving disability agencies autonomy and flexibility to move toward community-based services. There is evidence than an overly prescriptive approach to policy implementation can alienate those who need to embrace reform. They may see little merit in the changes, and indeed may find them threatening. New Public Management (NPM) approaches to governance are reflected in the Government's Value for Money and Policy Review of Disability Services. This review calls for the introduction of competitive tendering, detailed Service Level Agreements outlining the annual contract between HSE commissioners and service providers, and performance targets monitored against discrete outputs. It may be that this approach does not facilitate change in organisations where the proposed changes conflict with an agency's organisational ethos. Experimentalist approaches to governance, which promote a more iterative response to change allow stakeholders to meet broad service goals at local level, in close collaboration with commissioners. Those driving reform need to consider whether a prescriptive NPM approach to implementing change will facilitate the scale of reform required in disability service provision.

In the absence of clear direction on how service delivery will transfer to community-based services HSE was deemed by many stakeholders, including representatives of HSE, to show a lack of leadership. During the time when stakeholders were consulted for *Moving Ahead* a series of committees were in place to examine how reform may be implemented. There was general consensus that these committees were not effective, promoting some stakeholders to refer to implementation to date as 'death by committee'. It should be noted that these committees were stood down and a new suite of committees established within HSE. This fragmented approach to implementation is a barrier to community-based services which have been delayed as new structures are put in place.

Others felt that the seemingly lack of drive from HSE was being used as an excuse for lack of progress within resistant agencies. Of concern is that in the absence of any real leadership from HSE disability service providers are likely to gravitate towards the familiar and continue service delivery reflecting their organisational ethos. Those who promote a philosophy of care over support may engage in what the Government have acknowledged is a 'slow and tentative drift' towards policy implementation. There is substantial evidence from Professor McConkey's review of service provision from 1999 to 2009 and from data gathered in *Moving Ahead* that progress towards community-based services is almost negligible in some areas of the country. Data for both pieces of research was taken from the National Intellectual Disability Database. Evidence from *Moving Ahead* would suggest that some of these data may underestimate the level of reform required due to insufficient detail on individuals' living arrangements. In particular, clusters of community houses may not be captured as congregated settings. Agreed definitions of living arrangements would facilitate accurate monitoring of progress towards community services.

The HSE environment itself may be identified as a barrier for reform. *Moving Ahead* identified low morale, risk aversion, and an uncertain future within HSE disability services. Many felt that HSE

would become a commissioning only body in time but no clear communication had issued. There was an expectation that movement to a commissioning role may enable commissioners to have more authority in their dealings with agencies. To date, commissioners were highly critical of their limited power in sanctioning poor performance or rewarding good practice of those delivering services. Some argued they should have the authority to instruct agencies to incrementally transfer set proportions of their budget to community services, a practice they had observed in other international jurisdictions. The ability of HSE to reward good performance and sanction poor performance of disability providers would facilitate the migration of services towards the community.

Commissioners were also hampered in their dealings with agencies as current financial systems do not allow them align the budgets they award to providers with specific units of service. While budgets may increase and decrease annually depending on the population of people supported, little data exists on the original agreement from which these debits or credits are made. Commissioners called for the introduction of zero-based funding where their allocations to providers are based on specific units of service delivered to particular individuals. Greater transparency in budget allocations, using the schedules in Part 2 of the Service Level Agreements between commissioners and agencies, would facilitate commissioners to understand precisely how funding allocations are being allocated towards community or congregated supports.

Central to this type of financing is the introduction of individual budgets for people with disabilities which would calculate a discrete budget for each individual based on support need. Many stakeholders expressed their frustration at the significant delay in introducing this type of resource allocation. They also commented on the need for brokerage independent of disability agencies to guide individuals in how they might use their budget to commission supports. The lack of individualised budgets, and brokerage infrastructure, was identified as a major barrier to individuals moving to the community using a 'money follows the person' approach.

Lack of finance was unsurprisingly cited as a major barrier to the implementation of community-based services. A review of HSE National Service Plans in *Moving Ahead* clearly illustrated the impact of the recession on the delivery of service provision from 2008. To 2012, financial cuts cumulating to 10.5% were called for in disability services. National pay agreements meant that financial cuts were sought from back-room, non-pay efficiencies and were not to impact on direct service provision. Evidence from *Moving Ahead* suggests these cuts did impact on direct services. Most obviously, the financial situation hampered agencies' access to appropriate housing which resulted in an over reliance on respite services. The financial situation also heralded a return to group-based activities for people with intellectual disabilities. There is also evidence that the financial climate resulted in some agencies developing independent living options in clusters to reduce costs. Lack of finance can be identified as a barrier resulting in a regression in some agencies to congregated support.

The financial recession was also responsible for a moratorium on staff recruitment. Agencies were now more likely to rely on agency staff and volunteers, a practice that was universally thought to result in inconsistent and fragmented support. The moratorium was particularly problematic for HSE commissioners who had previously diverted funding from retired staff in congregated settings to new posts in community-based services. Despite the staff moratorium and presence of national pay agreements, some stakeholders argued that the disability sector was very well funded and that significant efficiencies could be gained by changing rosters to avoid premium payments to staff working anti-social shifts. Stakeholders noted that some staff and their respective unions were resistance to any changes in their terms and conditions, and their access to premium payments.

While largely cited as a barrier, finance was also identified as a facilitator to the development of community services. Some stakeholders described how their agencies had become more creative in their delivery of new services. Traditional methods of delivering services were challenged and

services were now more reliant on mainstream services which they deemed reflected the spirit of recent policies.

Barriers and facilitators within the community were cited by many stakeholders. Dominant among these was the location of the person's living arrangements. Some families, in particular those whose family member had high support needs, expressed a preference for more isolated locations within large grounds. Some families feared that people with disabilities might become targets for abuse living in dispersed housing in the community, however there was some consensus that this may be historical and that currently attitudes to disability were more favourable.   Some stakeholders expressed concern that the location of some local authority housing was in areas of social unrest or ghost housing estates. Other stakeholders recommended that individuals with disabilities should be centrally located within their own communities, where they would be known by natural supports such as neighbours and would be facilitated to engage in local activities. For many stakeholders access to transport was an issue of concern. People with intellectual disabilities, particularly those living in rural areas, could become isolated without easy access to transport. Suitable locations with good access to transport are key facilitators of community living.

Concerns were expressed about the capacity of HIQA, the statutory regulation and standards authority to monitor the quality of community based living arrangements. HIQA inspections of 'designated centres' were about to commence during *Moving Ahead*. Stakeholders were unclear as to whether 'designated centres' included all community-based living arrangements, and queried what role might HIQA play in the inspection of independent living arrangements for individuals who hold their own tenancies. Stakeholders also queried whether HIQA would make a determination of the level of choice individuals' expressed in where and with whom they live; key rights under Article 19 of the United Nations Convention on the Rights of People with Disabilities. The lack of clarity on how some community-based living arrangements may be monitored while respecting the rights of those living within their own properties is a barrier to community living.

Stakeholders were of mixed opinion regarding whether the wider community would be receptive to people with intellectual disability living in their community. Families were concerned that social capital within communities had reduced in recent years; neighbours were far less likely to call on each other and many housing estates now lie vacant during the working day. Staff delivering disability services were also concerned about discriminatory or anti-social behaviour. These fears are a barrier to people with intellectual disability moving to community living.

Some stakeholders were more positive in their outlook suggesting that the capacity of local communities is underestimated. Social role valorisation was identified as a vehicle that facilitates people with intellectual disability to meet other people in the community through roles not typically afforded to people with disabilities such as consumers, sports players and community activists. These platforms promote possibilities for people with intellectual disabilities to engage with natural supports in the community, a key facilitator maintaining community living.

Moving Ahead sought the opinion of mainstream community services on their capacity to provide support to individuals with intellectual disability within local communities; these mainstream services included employment, health and housing. Stakeholders representing mainstream employment services worked within areas of their organisations that specifically support individuals who have traditionally been excluded from the workforce. These stakeholders felt ill-prepared to support individuals with intellectual disability to obtain work as they could not provide the level of one to one support needed to bring someone to the point of being 'job ready'. Practical issues also arose, notably the benefits trap where individuals who earn over a certain amount lose part of their social benefits. These stakeholders called for collaboration from disability organisations in preparing individuals for the workplace.

Mainstream health services were limited to discussions of primary care, the proposed route through which people with intellectual disabilities will have their health needs met. This stakeholder group had considerable concerns about the capacity of an already over-stretched primary care system to provide supports to individuals who were deemed to receive optimal health services within disability services. Concerns were also expressed that no formal negotiations had been made with bodies representing the medical profession. These concerns represent a major barrier to people with intellectual disability living in the community.

Mainstream housing services are distinguished from other mainstream services participating in *Moving Ahead* as having a formal negotiation with disability services through the National Housing Strategy for People with a Disability. The strategy identifies social leasing, through housing associations, as the preferred housing model for people with intellectual disability. People moving from congregated settings are prioritised within the strategy to move to community living. The use of formal negotiations between mainstream housing and disability organisations has been a facilitator in progressing mainstream housing for people with disabilities, albeit teething problems have arisen.

Concerns were expressed about the trend for disability organisations to establish their own housing associations as a vehicle to source accommodation for the people they support. Mainstream housing providers questioned whether disability agencies had the necessary expertise to manage these associations. They also expressed concerns as to whether disability organisations would commit the necessary social support to individuals living in local authority social housing. Local authority welfare officers were deemed not to have capacity to support individuals with intellectual disability in social housing. The finer detail of arrangements between housing authorities and disability agencies was under negotiation at the time of these *Moving Ahead* interviews in a draft set of national protocols. A lack of clarity on roles and responsibilities between housing and social care providers could become a significant barrier to community living.

Difficulties were identified for people with intellectual disabilities accessing mainstream housing; mindful that this system was in its infancy during the time of the *Moving Ahead* interviews. Firstly, data on the numbers of people with intellectual disability seeking mainstream housing was questionable. The main source of data, the Housing Assessment Survey, was deemed problematic for people with intellectual disability. Accurate data on the numbers of individuals requiring mainstream housing is a prerequisite for future planning.

Eligibility for social housing within local authorities was also problematic as it differs by local authority; decision making regarding eligibility is a reserved function of local counsellors. This means that different strategies are used by different local authorities to allocate housing to those on the housing list. Disability per se does not prioritise people on the housing list however some local authorities prioritise 'welfare groups' which may include people with disabilities. In contrast, some local authorities may deem people with disabilities who are housed by disability agencies as 'adequately housed' and therefore ineligible for social housing. This variation can sometimes occur both between and within local authorities. Continuity across all local authorities is required in the allocation of social housing to people with intellectual disability.

A number of practical issues were also emerging in the early implementation of the housing strategy: some forms were deemed inaccessible for people with intellectual disability; rent supplement was refused for some individuals who were receiving other social benefits; some applications required utility bills which individuals living in congregated settings would not possess. These issues, and others, were being addressed with the support of the National Federation of Voluntary Bodies (NFVB), an umbrella organisation representing non-government disability providers. The partnership between mainstream housing services and NFVB has been a significant facilitator in addressing barriers to community living.

The progression from disability to mainstream services has been most successfully achieved with regard to housing. This progress can be largely accredited to a high level partnership between housing and disability services. While teething problems have arisen, the formation of a National Housing Strategy has created awareness among relevant stakeholders, created a forum for negotiation, and clarified the roles and responsibilities of stakeholders. Similar strategies in other areas such as employment and health may resolve some of the challenges noted by those working in mainstream services in these fields.

What role do organisational culture and ethos play in developing community-based living?

The eight organisations participating in *Moving Ahead* represented three organisational types: HSE organisations providing a range of residential options from institutions to community-based living arrangements (2); large non-statutory organisations (NGOs) providing a range of options from campus-based settings to community-based living arrangements (3); and small non-statutory agencies which have only ever provided community-based living options (3).

Direct support staff and clinicians all report with conviction that the supports they provide are optimal, albeit that recent cuts have impacted negatively on the support their organisation can provide. Where their opinions differ sharply is in their descriptions of the culture within their organisations. HSE staff describe their culture as institutionalised where employees feel frustrated and demoralised, seeing little opportunity for promotion. More positively, they state that they provide good care to those they support and they work in an environment with good peer-to-peer support among colleagues. Staff in large non-statutory organisations also spoke of an institutionalised and hierarchical culture but were more positive stating their organisations were client-centred, team-led, progressive, and embraced a culture of change. Staff in smaller non-statutory organisations described their organisational cultures as evolving, progressive, person-centred and individualised.

The specific comments around management are important within the broader context of organisations facing a major reconfiguration in day to day practices. These managerial comments were not prompted by the research team but were spontaneously generated by staff when asked about their organisation culture. Staff in both HSE organisations reported no confidence in management. Staff in large NGOs were less critical describing their management as hierarchical and inconsistent. Staff in small NGOs described a radically different relationship with management, one characterised by a relaxed nature with easy access. These descriptions of the relationship between staff and management suggest a clear differentiation between agencies that are charged with implementing widespread policy reform across the disability sector.

Those working in HSE and large NGOs are required to make the most change to meet policy objectives. Those in smaller NGOs have only ever provided community-based services, but are not immune to the introduction of new practices based on recent policies. The perception of management within HSE and large NGOs suggests that these organisations will face the greatest hurdles in implementing change largely based on the fact that those who are pivotal in introducing reform at the ground floor level have little or no confidence in the ability of management. It may be that those who seek to work in smaller organisations do so precisely because they align to an ethos of community-living; those who seek to work in larger organisations may do so because they seek greater on-site collegial support, by definition more plentiful in large organisations. Or it may be that individuals through their daily interaction with peers assimilate the culture of the organisation where they work. Both explanations likely play a role.

Awareness of policy among front line staff also seemed to distinguish these three organisational types; those in HSE and large organisations were less aware of policy, in some cases being required

to sign off on reading a policy document. This tokenistic gesture can be contrasted with staff in smaller organisations who were far better informed about recent policy, perhaps unsurprisingly given their greater access to management.

The vision of policy reform, instigated by HSE, has clearly not been communicated to those at the forefront of service delivery. Without a clear understand of the rationale for introducing change or seeing how policy can directly improve the quality of service delivery, there is little reason to expect anything other than resistance from staff, notably HSE, who describe an environment whether there is little accountability to higher management for any day to day activity. Reflecting the commentary on HSE's national implementation on policy, it seems no one is demonstrating leadership at agency level in HSE. This finding is a cause for concern when placed within the context of other findings from HSE indicating that direct support staff perceive person-centred planning as 'a bit of a waste' and of more relevance for organisational compliance that individuals' quality outcomes. The failure to grasp the importance of person centred planning should be noted and acted upon speedily by effective management.

Resistance to reform is overcome where management introduce new cultural beliefs, pass on new values to staff and are seen to adopt the practices they preach. Where policy goals are misaligned to management vision and onward to day to day practices, change is unlikely to be welcomed. Employees are likely hold to their strongly held values and be unable to detach from their former ways of working. *Moving Ahead* has found instances where management vision and day to day practices are incongruous with current policy. At the level of senior management within organisations clear differences were found in their perspectives on service delivery. Smaller organisations were unanimous in their support of mainstream housing options for people with intellectual disability. Some had long-standing relationships with mainstream housing associations; others were currently cementing these relationships. These organisations typically do not perceive themselves to be providing housing in the future; rather this service will fall to generic housing associations. In contrast, senior management in some HSE and large organisations continue capital investment in housing or are establishing their own housing associations. These activities may be seen to contravene the spirit of policy reform calling for the separation of housing and social care support.

More fundamentally, senior management differ in their views on the imminent closure of congregated settings; small NGO management are of the opinion these settings must close, larger organisations spoke of their support for 'modern cluster' developments, while HSE management stated that they would accept clusters in light of the dormitory style accommodation of some of their institutions. The inconsistency between policy and practice is also seen at the level of commissioning where HSE agencies and large NGOs were both critical of the ongoing pressure they face from HSE to admit individuals to their congregated settings, a practice that is clearly in breach of the recommendations of HSE's own review of congregated settings '*Time to Move On from Congregated Settings'*.

It light of these inconsistencies between organisational practice and policy, it is not surprising that staff working in some of these organisations are highly critical of management. The policies are poorly explained, devoid of any relevance and are not taken seriously by some senior management. It is for this very reason that proponents of deinstitutionalisation have argued that it is simple not feasible to leave the process of deinstitutionalisation within the remit of those delivering services (Mansell et al, 2007). Professor Jim Mansell, a leading international authority in the field of deinstitutionalisation, came to this conclusion qualifying his commentary by stating that regional and national governments must drive the process of reform. In light of the commentary from HSE commissioners participating in *Moving Ahead*, it seems that at regional level there is some motivation but little authority to drive reform. A similar situation is present at national level where initial

committees charged with implementing policy were stood down and the effectiveness of a suite of new HSE implementation committees has yet to be demonstrated. In the absence of any apparent leadership, it is unsurprising that many disability agencies have reverted to their own familiar style of service delivery.

As the 'slow and tentative drift' noted by the Value for Money and Policy Review of Disability Services continues in some regions, those who receive these services also gravitate towards the familiar. People with intellectual disabilities and their families showed a strong preference toward their current living arrangement. This was most evidenced for those availing of congregated settings where those who live in these settings and their family members were isolated in their favourable opinions of these living arrangements. The vast dearth of advocacy services nationwide means that many of the people who avail of congregated settings have no opportunities to meet with others to determine how people with similar support needs are being supported in the community in other regions nationwide. This type of peer to peer support would be hugely valuable to allay concerns and present a spectrum of currently unknown living opportunities.

Organisational culture has played a key role in the development of community-based living in the three types of organisations participating in *Moving Ahead*. It would seem that the intersection between direct support staff and management is crucial in defining the organisational culture in these organisations. Those managers who have embraced the change agenda were more likely to be found in smaller organisations. Whether these individuals could exercise their vision with similar impact within a larger scale organisation is open to debate. What is clear is that these managers have convinced their existing staff and/or newly recruited staff to follow their leadership. Within larger organisations the opportunities for direct contact between senior management and direct support staff are likely fewer, but other opportunities must be creatively considered to encourage and not alienate concerned staff.   The words and actions of all management must be seen to reflect their convictions.

What factors distinguish residential provision in the two regions?

Data from NIDD examined in *Moving Ahead* illustrated that clear differences remained between the two study regions subsequent to Prof McConkey's original research illustrating differences in living arrangements in these regions. The factors that distinguish these regions shall initially be prioritised in relation to Region1, the area with less progression to community living, and later prioritised in relation to Region 2.

Region 1, in comparison with Region 2, is larger and delivers residential centres as its most dominant living arrangement for those living outside the family home. The region has an approximately equal split of community-based and congregated living arrangements (as defined by NIDD), and is more likely than Region 2 to support younger people in congregated settings, and people with low support needs in community group homes. Few people have moved to community-based living arrangements in the five years previous to *Moving Ahead*, a sharp contrast to considerable progress made in Region 2. Of significance is the similar demographic profile of people with intellectual disability in the two regions. These findings indicate that the main driver of disparity between service provision in the two regions is not the characteristics of the individuals supported, but rather the use of seven day residential centres within Region 1. Put simply, these centres are used in Region 1 because they exist in Region 1.

The *Moving Ahead* survey, while limited by missing data in some parts, provided some detail on the profile of people living in both regions. Similar patterns emerged whereby service delivery differed in the absence of any difference in the support needs of the people using these services. People living

in Region 1 were more likely than those in Region 2 to move to a congregated setting in the previous five years, and were less likely to live in the community if they had higher support needs. The quality outcomes of individuals supported in the two regions did not differ per se, but the quality of life of individuals did differ depending on whether or not they lived in the community; those living in the community experiencing better quality outcomes. The dominance of congregated settings in Region 1 suggests more individuals are likely to experience diminished quality outcomes in this region than in Region 2.

Differences were observed among the commentary from various stakeholders depending on their region. Cluster housing is identified across a number of stakeholder groups as a highly distinguishing factor. People with intellectual disabilities themselves were more favourably disposed to these living arrangements if they lived in Region 1. This preference is reflected by a significantly greater tolerance of cluster arrangements by senior management in Region 1 where 'modern clusters' and 'supported independent living clusters' are advocated. Region 2 has actively discouraged the development of clusters, either on campus or in communities. The preference for cluster style housing is accompanied by a lower and less successful level of engagement with mainstream housing bodies in Region 1. Essentially, Region 1 continues to prioritise disability specific housing, owned and managed by disability providers over mainstream housing provided by housing associations or local authorities.

Of perhaps greatest significance however is the historical progress towards deinstitutionalisation in the two regions, and as has been evidenced in other jurisdictions, the far reaching impact of decision making by one individual in a position of authority. The deinstitutionalisation literature has many individual champions who, without the might of national policy, have speared-headed reform. Over 30 years ago one such champion in a position of authority began a process to divert all services to the community in Region 2. The process has now culminated in a 'no new admissions' policy to congregated settings, no cluster developments, a trend towards personal tenancies, and a prioritisation to move individuals to more independent living arrangements.   These developments occurred outside of the glare of national policy which may have afforded the type of flexibility in governance noted in experimentalist approaches. The developments also occurred during a time of relative economic stability, and in later stages during an economic boom which likely aided progress given the commentary on the negative impact of the recession by many *Moving Ahead* stakeholders.

Another highly significant difference between the regions was the authority shown by HSE commissioners five years previous to *Moving Ahead* to refuse plans for a cluster setting. This is a pivotal decision. This decision was made prior to the publication of HSE's review of congregated settings which advocated the closure of these settings and illustrates the type of regional and national leadership called for by Professor Jim Mansell. While commissioners complained bitterly at their lack of authority to sanction or reward service providers, this decision has provided key leadership and direction to agencies as to the future development of services in this region. Mainstream housing has become the expectation, and this is reflected in more mature relationships between providers and local authorities in this region.

A final and notable difference within regions is the establishment of a regional committee in Region 2 to examine regional referrals for accommodation in a standardised and transparent manner with all key stakeholders represented. This committee prioritises the possibility to secure more independent living options for the individuals referred. The establishment of this committee ensures that all key stakeholders have input into the direction of future service delivery in this region.

What role do local and regional issues play in developing community-based living?

In addressing this question, 'local' will be used as a proxy for individual organisations delivering services, while 'regional' will refer to the broader context, notably commissioning.

Local issues play a significant role in the development of community-based living arrangements, most especially in Ireland where non-statutory agencies have enjoyed considerable autonomy in how they deliver services. Over time, these organisations have developed their own cultures and ethos in their understanding of best practice in supporting people with intellectual disability. Within this context these agencies have had relative freedom to decide on their preferred model of residential services. This autonomy is evidenced in *Moving Ahead* where senior agency personnel have identified areas of national policy which they feel they can implement, and other areas which they feel do not reflect their own service delivery.

For organisations prioritising a care ethos the development of more congregated style arrangements is likely, in particular cluster living arrangements. For those with a focus on providing more independent supports clearly dispersed independent living options are more likely. The implication for those receiving services is that their choices are limited by the availability of a small number of provider organisations in their catchment area. Whichever type of living arrangement is preferred by these agencies becomes the lived experiences of not only people with disabilities, but also their families and staff. This lived experience, as evidenced in *Moving Ahead*, is highly likely to become the preference of these stakeholders; a preference which is more often than not resistant to change.

Of particular significance at local level is the ethos of the larger organisations. By definition they represent a considerable proportion of the living arrangements within a region, and any developments within these organisations have significant implications for people living in their catchment area. Those larger organisations represented in *Moving Ahead* were also long-standing and therefore are in transition from congregated to community supports. *Moving Ahead* has shown that large organisations are likely to face resistance from many stakeholders as they move towards community-based living options. Targeted support here would make a considerable difference to the living arrangement options available for people with intellectual disability within their region.

Regional issues have been found to be of central importance in *Moving Ahead*. A historical decision within one region has culminated in significant gains towards deinstitutionalisation. While there is still work to be undertaken in this region, the intersection of leadership at commissioning level and organisational ethos at agency level has become formalised within a regional level referral committee. Put simply, the autonomy of individual agencies has become part of a larger context with shared aims and a clear direction. Individual autonomy is still practiced, but in core issues such as the development of cluster housing arrangements, group decisions rule.

In conclusion, *Moving Ahead* has attempted to identify the interplay between those receiving services, those delivering services, and those commissioning services within two differing regions in Ireland. The findings suggest that first mover advantage has benefitted those who live in a region where leadership is shown and where collaboration is encouraged.

Required Actions

The following core activities should be prioritised in order to facilitate greater progress toward the development of community-based services.

• Agreement is needed on the development of a comprehensive and accurate dataset to implement current policy. The dataset needs information on people moving to the community, the process of moving, training, outcomes, community connectedness, and costs. Information is also required on the views of people with disabilities and their families and lessons learned from their experiences.

• Agreement is needed on definitions used to describe different types of living arrangements: dispersed housing, cluster living arrangements, independent living etc.

• A comprehensive communication strategy is required that is accessible to key stakeholders. The strategy should include workshops focus groups, DVDs, and opportunities for individuals who have moved to community living arrangements from congregated settings to meet face-to-face with others, most especially people with intellectual disability, families and staff.

• Clarity is needed on the expectations for those services involved in implementation, notable the role and responsibilities of HSE, and of those delivering services.

• Consideration is required to identify and agree the most suitable governance model to deliver on the proposed policy reforms.

• A detailed and comprehensive implementation plan is required that will address national as well as local issues. This plan should include resources, housing, communication, staff training, change management, manpower development, etc.

• A clear statement is required on the current status of the HSE report *Time to Move on from Congregated Settings*, and its recommendations.

• More access to independent advocacy for people with intellectual disability and their family members is required.

• Strong partnerships are required between disability agencies and local community groups, with disability agencies taking a leading role in this collaboration.

• The role of mainstream housing associations needs to be developed.

• A specific strategy is required to address potential loneliness and isolation of people from congregated settings who move to the community.

• Significant investment is needed to ensure staff are trained in highly personalised support strategies such as 'active support'.

• Consideration is required for those who have high support needs, such as those who are elderly or who have significant health needs.

• More time is needed to ensure that people moving to the community have trust in the process, have appropriately planned moves, and have received clear and appropriate communication.

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