FROM CONGREGATED TO COMMUNITY LIVING

MOVING AHEAD

Executive Summary

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This report is an executive summary of the findings of a research project entitled *Moving Ahead*. The project aimed to examine factors that contribute to the successful transfer of people with intellectual disabilities from congregated to community-based living in two regional areas in Ireland. It was undertaken by a team of researchers from Ireland and the UK, led by Dr. Christine Linehan. The research received funding from the Health Research Board's *Health Research Awards 2012-2014*.

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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.

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

Rationale and Method

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.

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.

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.

Moving Ahead Focus Groups and Interviews with Key Stakeholders

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 due to 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 simply 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 housing provided by mainstream 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 leadership called for by Professor Jim Mansell. While commissioners in *Moving Ahead* complained bitterly at their lack of authority to sanction or reward service providers, the decision to effectively cease cluster housing options 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 mainstream 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 for 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 regional and 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 is required to independent advocacy for people with intellectual disability and their family members.

- 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.