

## ***Summary of Moving Ahead***

The following decade is likely to realise the closure of all congregated settings and the development of more personalised community-based services for people with intellectual disability in Ireland. The pace of change however is uneven throughout the country. *Moving Ahead* sought to examine why such variation exists. *Moving Ahead* was funded by the Health Research Board and led by Dr Christine Linehan at the UCD Centre for Disability Studies, University College Dublin (formerly of Trinity College Dublin).

*Moving Ahead* selected two regions in Ireland which differed markedly in the rate at which people with intellectual disability were moved from larger campus-based settings to smaller, dispersed housing in the community. Within each region four agencies providing services for people with intellectual disability were invited to participate. These agencies included HSE services (providing institutional and community-based housing), large non-statutory agencies (providing campus-based and community-based housing) and small non-statutory agencies (providing community-based housing only). The participating agencies accounted for 65% of all services delivered in the two regions.

The agencies acted as recruiters for participants with intellectual disability, family members, direct support staff, clinicians, senior agency personnel and regional HSE commissioners. Other stakeholders participating in *Moving Ahead* included individuals involved in a range of allied fields at national level including policy, standards, advocacy and housing. In total 354 people participated in *Moving Ahead*.

A review of the National Intellectual Disability Database at the start of the study revealed that while the demographic profile of people supported in the two regions did not differ, one region was characterised as offering residential centres as the most dominant form of living arrangement, supporting younger and more able individuals in these residential centres, and by moving substantially less people to smaller community-based housing in the preceding five years. Given the similar demographic profile of people supported in the two regions, factors other than support needs seemed to be driving the disparity in progress towards community living.

A survey of 136 adults with intellectual disabilities supported by participating agencies in the two regions was conducted to examine differences in the manner in which individuals were supported in both regions. An unexpected finding was the lack of consensus from participants and their support workers on what precisely comprised community-living. The survey findings indicated that individuals' 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 far more likely to live in congregated settings. The survey also revealed that it is individuals' living arrangements, rather than their support needs, that influence their quality outcomes (e.g. opportunities to express choice, level of community engagement). The fact that regional factors do not seem to influence quality outcomes suggests that changes in living arrangements to smaller, dispersed housing in these regions will contribute to greater quality outcomes.

In addition to the survey, 22 focus groups and 42 interviews were conducted with 218 key stakeholders; people with intellectual disability (42), family members (40), direct support staff and clinicians (94), senior personnel (19), HSE commissioners (6) and regional and national experts (17). Participants were asked about their views of current living arrangement options and to identify barriers and facilitators to community-living. Participants' views of current living arrangements seemed heavily influenced by their own experiences, notably for those directly using or delivering services. Participants' knowledge of residential options apart from those they currently received, and of national policy driving the introduction of newer options, was poor. Independent living options were distinguished by generating most commentary among stakeholders as to what precisely it comprised. Cluster living arrangements, defined as congregated settings where dwellings were located on a campus or in close proximity in the community, were a strong discriminator between the two regions; in one region these settings were actively promoted, while in the other region they were actively resisted via a decision some years previous to cease funding for cluster settings. In general, developments in the two regions were distinguished by their choice of deviation from community group homes; in one region cluster settings were favoured, in the other region independent living options were promoted.

Key barriers and facilitators to community living were identified by all stakeholders:

- Good support, advocacy, and opportunities to exercise choice all facilitated community living.
- High support needs (age, medical need, behaviours that challenge etc.) were deemed a barrier.
- The family were pivotal in 'making or breaking' a move to the community.
- The relationship between family and direct support staff is crucial; some families described poor relationships and the need for constant vigilance.
- Poor communication of recent disability policy is a significant barrier to change; notably what changes are proposed and who is responsible for driving change.
- There is widespread mistrust of the proposed changes; many perceive a mixed message of economic cuts and changes in service delivery as being causally linked.
- Many stakeholders are unaware of demonstration projects showcasing good practice.
- Senior Management and Commissioners expressed concerns about the long-term financial viability of demonstration projects.
- Concerns were also expressed that many direct support staff do not have access to training sessions, seminars and conferences showcasing good practice.
- Empire building, whereby some agencies have amassed large property portfolios may conflict with proposed move towards tenancies and mainstream housing options.
- There is no standardised approach to implementing new policies; albeit specific outcomes are identified under the Value for Money and Policy Review of Disability Services.
- A prescriptive approach to implementation (New Public Management Approach) may conflict with agencies' need to experiment with new models of support (Experimentalist Approach).
- Many perceive HSE to show a lack of leadership in the implementation of new policies leading to a fragmented approach.
- A lack of leadership by HSE facilitates some service providers to engage in 'more of the same', a pattern acknowledged by Government as a 'slow and tentative drift' to policy implementation.
- Monitoring implementation using the National Intellectual Disability Database may underestimate the level of reform required as community clusters may be unrecognised as congregated settings.
- Commissioners are hampered to incentivise well-performing agencies and sanction poor performance.
- Commissioners require 'zero-based funding' to clarify the association between funding units and delivered services.
- The delay in introducing individualised budgets is a significant barrier for those wishing to move to more individualised living arrangements.
- Reliance on agency staff and volunteers due to a staff moratorium was deemed to result in uneven and fragmented support.
- Some stakeholders perceive the disability sector well-funded when compared to other voluntary sectors and note that resistance to the introduction of more personalised services has been linked to access to premium payments.
- The economic recession had forced some agencies to be more creative in service delivery and more reliant on mainstream services.
- Stakeholders had mixed views on whether people with intellectual disability would be welcomed within local communities as social capital was thought to have diminished in recent years. Suitable locations were a key requirement.
- The role of HIQA in inspecting personalised living arrangements was unclear for many stakeholders.
- Those working in mainstream employment services and mainstream health services felt ill-equipped to support people with intellectual disability; those in mainstream housing were distinguished as drafting a national strategy to guide their services to best support for people with disabilities.
- The growing trend for disability agencies to develop housing associations was a concern for mainstream housing providers who questioned whether the relevant expertise was available.
- A raft of difficulties was cited for people with disabilities accessing mainstream housing, albeit noting the national housing strategy for people with disabilities is in its infancy.

Organisational culture has played a key role in the development of community-based living in the participating agencies.

- Distinct organisational cultures were observed for those working in HSE, large non-statutory and small non-statutory agencies. HSE staff report feeling demoralised with no confidence in management. This contrasts with small agencies where the culture is described as person-centred

and progressive. The culture in large non-statutory agencies falls somewhere in between HSE and smaller organisations.

- Person-centred planning in HSE was described as ‘a bit of a waste’ and of more relevance for organisational compliance than for individuals’ quality outcomes.
- Those working within HSE and larger organisations will be required to introduce the most change in service delivery; these are also the organisations where confidence in management and knowledge of new policy is less than optimal.
- Some agencies continue to engage in practices that are incongruous with current policy; notably the promotion of ‘modern clusters’ in the community by some HSE and larger organisation representatives.
- The interface between management and direct support staff is crucial in defining organisational culture. In general, management in smaller organisations have embraced change and successfully communicated this ethos to staff; management in HSE and larger organisations must be supported to do likewise. The words and actions of management must be seen to reflect their convictions.

Regional differences were identified at commissioning level which influenced the development of community-based living in the two regions.

- One region delivers residential centres as its most dominant living arrangement for those living outside the family home, supports younger people in congregated settings, and supports people with lower needs in community group homes. Few people have moved to the community in the last five years despite the similar demographic profile in the two regions.
- Stakeholders in this region express a preference for ‘modern clusters’ and ‘supported independent living clusters’.
- Engagement with mainstream housing is less successful in this region.
- The region which has made significant progress towards community living commenced a community-living policy over thirty years ago, spearheaded by a champion. This process has culminated in a ‘no new admissions’ policy to congregated settings, no cluster developments, a trend toward personal tenancies, and a prioritisation to move people to more independent arrangements.
- These developments occurred during a time of economic boom which likely aided progress.
- The decision by HSE commissioners in this region to cease funding cluster arrangements was a pivotal decision in shaping the future of service delivery in the region.
- This region now hosts a referral committee where all service providers discuss incoming referrals in a transparent and timely fashion.

In conclusion, *Moving Ahead* has attempted to address a key gap in the evidence on deinstitutionalisation: why do regional disparities occur? Local issues play a significant role in the development of services, notably in Ireland where non-statutory agencies enjoy considerable autonomy. Over time these agencies have developed their own organisational culture which becomes reflected in the type of services they provide. These services become the lived experiences of management, staff, families and people with intellectual disability; and this familiarity often becomes people’s preferred model of service, a preference that is typically resistant to change. Of particular significance at local level is the ethos of large non-statutory agencies, which by definition represent a considerable proportion of living arrangements within a region. How these agencies choose to deviate from community group homes, typically to community clusters or independent living options, is a key determinant of service delivery within the region. Where these decisions are integrated into a regional level structure, such as the regional committee described above, progress has been made. A ‘slow and tentative drift’ towards progress is seen where agencies are facilitated to pursue a care model favouring larger, more segregated settings despite considerable national policy opposing the development of such services.

*Moving Ahead* has produced four reports:

- (1) Executive Summary
- (2) Main Report
- (3) Scoping Review of Research
- (4) Policy Review