Models of Residential Provision for People with Disabilities

A Contemporary Developments in Disability Services Paper

The aim of this paper is to outline a variety of residential supports that are currently available for people with disabilities and to highlight those options that provide optimal quality supports for residents. The selection of these models is informed by an ongoing programme of work undertaken by the National Disability Authority on independent and community living options for people with disabilities. This work has comprised information gathering on residential options in international jurisdictions via site visits and expert informants, an examination of peer-reviewed literature on quality outcomes in residential supports, dissemination of research and practice at conferences and seminars and ongoing consultation with stakeholders.

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1.1 Aim

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1.2 Irish Context

The National Intellectual Disability Database[1] and the National Physical and Sensory Disability Database[2] provide annual data on individuals in receipt or waitlisted for specialist disability services in Ireland. Table 1 presents data from these databases for 2008 which reveal that the majority of those who are registered on the National Intellectual Disability Database live in the family home. Almost one-third live in full-time residential care, defined as either 5 or 7 day per week residential placements. A minority is classified as living in 'independent settings'. Data for those registered on the National Physical and Sensory Disability Database similarly reveal that the majority live within the family home. Almost one in ten is classified as living alone. A minority live with 'non-family', of whom over half are defined as living in full-time residential services. Both databases have seen increased demand for residential services, and within the context of greater life expectancy among people with disabilities, this demand is likely to continue.

Table 1: Main residential provision for people with intellectual, physical or sensory disabilities in Ireland, 2008		
	%	n
National Intellectual Disability Database		
Living in the family home	64.2%	16,708
Living in full-time residential care	31.8%	8,290
Living in independent settings	3.7%	950
National Physical & Sensory Disability Database		
Living in the family home	86.1%	23,500
Living alone	9.5%	2,591
Living in full-time residential services	2.6%	697

Any review of residential supports should take into consideration the obligations of the UN Convention on the Rights of Persons with Disabilities[3]. The Convention requires state parties to facilitate the full inclusion and participation of people with disabilities in the community by ensuring that firstly, "persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement". Secondly, "persons with disabilities have access to a range of in-home, residential and other community support services, including personal

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[1] http://www.hrb.ie/health-information-in-house-research/disability/nidd-publications/ Retrieved 2 December 2009.

[2] http://www.hrb.ie/health-information-in-house-research/disability/npsdd-publications/ Retrieved 2 December 2009.

[3] http://www.un.org/disabilities/ Retrieved 2 December 2009

assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community". Finally, "community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs".

While full participation in community living is advocated, Ireland along with other international jurisdictions retains a continuum of residential supports ranging from large congregated settings through to individualised community-based supports. This brief review outlines some of the more typical residential options along this continuum and presents an overview of appraisal for each model.

1.3 Models of Residential Supports for people with disabilities

1.4 Framework of supports

A useful framework for classifying residential supports for people with disabilities is to distinguish between 'comprehensive placement' and 'separate accommodation' models. A comprehensive placement is defined where accommodation is purchased by government as part of a person's overall support package. This type of accommodation includes institutions, hospital wards, smaller specialist residential facilities, cluster housing and group homes. A comprehensive placement is typically staffed 24 hours per day and is financed by the residents' income from benefits which are paid directly to the service provider for accommodation and living costs. In contrast, separate accommodation is defined where residents live within a private residence, whether their family home or in their own home with appropriate supports. In this report shared living arrangements, whereby a person with a disability resides within a private home owned by a non-family member, will be also be classified as a separate accommodation option.

1.5 Comprehensive placements

Comprehensive placement models have traditionally received funding, either directly or indirectly from government, in the form of large service agreement grants. Service providers are allocated an agreed budget from which residential accommodation and other services are funded. In recent times, this funding mechanism has come under criticism as being inconsistent with person-centred planning on the grounds that it promotes the planning of residential places for pragmatic as opposed to resident-led reasons[4]. Residents may find themselves 'allocated' to a particular residence, not because it is their choice, but rather because they are waitlisted to avail of the next vacated place.

1.5.1 Institutional Settings

The appropriateness of large, institutional settings for people with disabilities has been debated at length. In many developed countries the policy debate over whether to provide institutional or community-based settings is 'largely resolved'[5]. The abandonment of these institutions and their replacement with smaller community-based dwellings "has probably been the most significant policy development in intellectual disability in the post-war period" (Mansell & Ericsson, 1996)[6]. The characteristics that are associated with institutional care are well

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[4] Victorian Auditor-General (2008). Accommodation for People with a Disability. Victorian Government Press.

[5] Mansell, Beadle-Brown and members of the Special Interest Research Group on Comparative Policy and Practice (2009) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, in press.

[6] Mansell J., & Ericsson, K., (Eds) (1996). Deinstitutionalisation and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA. London: Chapman & Hall.

evidenced and include 'block treatment', where groups of residents are supported en masse as opposed to being supported as individuals, 'depersonalisation', where possessions are communal, 'rigidity of routine', where scheduled activities such as dinner or bathing are timetabled, and 'social distance' where the roles of residents and staff are clearly delineated and hierarchical[7]. These characteristics are associated with poorer quality outcomes for residents and vigilance is required to ensure that they are not transferred to new services[8].

1.5.2 Specialist Residential Facilities

Smaller specialist residential facilities typically provide for ten or more persons with multiple and severe levels of disability. As a step-down option from larger institutional settings, these facilities are at risk of embedding some of the institutional characteristics defined above. The ICF-MR model ('intermediate care facilities for people with mental retardation or other developmental disabilities') throughout the US, provides an example of these facilities. The introduction of Medicaid waivers, relaxing the regulation that Medicaid federal funding be restricted to ICF-MRs, has supported the growth of more community-based supports across the US. Despite this diversion of funding with a view to encouraging community integration, the ICF-MR remains a leading form of residential provision throughout the US. In 2008, over one fifth of all residents in in US state and non-state residences were supported in ICF-MRs (n=93,164)[9]. In other jurisdictions such as the UK, policy recommendations oppose the establishment of this form of specialist residential settings for those with high support needs[10]. These smaller congregated settings continue as a form of residential support however[11], despite commitments to transfer residents to more appropriate settings[12].

1.5.3 Clustered Settings

Clustered settings, some of which may be classified as specialist residential facilities, are defined as three or more living units with an on-site day centre forming a separate community from the surrounding population[13],[14]. Although the proponents of clustered settings distinguish them from large residential institutions, both models are based on a campus model of support. Different formats of clustered housing include village communities, residential campuses and cluster housing. **Village communities** are generally operated by charitable foundations and tend to support more able residents who are supported by unpaid volunteers. These

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[7] King, RD., Raynes, NV, & Tizard, J., (1971). Patterns of residential care: Sociological studies in institutions for handicapped children. London: Routledge and Kegan Paul.

[8] Mansell, Beadle-Brown and members of the Special Interest Research Group on Comparative Policy and Practice (2009) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, in press.

[9] Lakin, KC., Larson, SA., Salmi, P., & Scott, N (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends through 2008. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

[10] Department of Health (1993). Services for people with learning disabilities and challenging behaviour or mental health needs. London: HMSO.

[11] Victorian Auditor-General (2008). Accommodation for People with a Disability. Victorian Government Press

[12] Disability Service Division (2006). Future Directions for Housing and Support in Disability Services. Department of Human Services, State Government Victoria.

[13] Mansell J, & Beadle-Brown J (2009). Dispersed or clustered housing for adults with intellectual disability: a systematic review. Journal of Intellectual or Developmental Disability, 34 (4) 313-323

[14] Emerson, E., (2004a). Cluster housing for adults with intellectual disabilities. Journal of Intellectual & Developmental Disability, 29, 3, 187-197

communities comprise a minority of accommodation services, (approximately 2% in England[15]). **Residential campuses** are defined as smaller residential units established within the campus of an institution. Residents typically have high support needs and have 24 hour paid staff in support. Following complaints regarding the quality of care in some of these facilities in England, the UK Government is committed to the closure of these campus developments[16]. **Cluster housing** is defined as a small number of houses on the same site, for example, forming a cul-de-sac of housing in a location where the wider community reside.

Recent work commissioned by the National Disability Authority has examined the available evidence comparing quality outcomes for residents in clustered and dispersed settings[17]. Dispersed settings were defined as housing arrangements comparable to that utilised by the general population. The evidence, comprising data on almost 2,500 individuals, found that clustered residential options generally provide poorer quality outcomes for residents than dispersed settings. While some benefits to clustered living were identified, such as access to health screening, these benefits generally applied only to village communities, which the authors state are "an important part of the spectrum of service provision but are only ever likely to occupy a niche in the market for care". The authors conclude "Dispersed housing appears to be superior to clustered housing on the majority of quality indicators studied" and "Clustered housing is usually less expensive than dispersed housing but this is because it provides fewer staff. There is no evidence that cluster housing can deliver the same quality of life as dispersed housing at a lower cost".

1.5.4 Community-based comprehensive placements

In contrast to the above specialised, and in many cases segregated forms of accommodation for people with disabilities, is the trend toward community-based residential supports. IASSID, the International Association for the Scientific Study of Intellectual Disability, provides a useful definition of **community living** in their forthcoming position statement on deinstitutionalisation and community living[18]. Community living is defined as comprising the same range of accommodation available to the general population, in the same locations where the general population reside, offering people with disabilities choice over where and with whom they live and providing the necessary supports for community participation.

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[15] Emerson, E., (2004a). Cluster housing for adults with intellectual disabilities. Journal of Intellectual & Developmental Disability, 29, 3, 187-197

[16] Mansell, Beadle-Brown and members of the Special Interest Research Group on Comparative Policy and Practice (2009) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, in press.

[17] Mansell J., & Beadle-Brown J., (2008). Dispersed or clustered housing for disabled adults: a systematic review. Canterbury: Tizard Centre. (p.6-7)

[18] Mansell, Beadle-Brown and members of the Special Interest Research Group on Comparative Policy and Practice (2009) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, in press.

The evaluation of community-based options, compared with the institutional type settings they sought to replace is clear. Community-based services are superior to institutions[19],[20],[21],[22],[23]. The argument suggesting that institutional settings may be less expensive than community models, is also clear. The European Commission's Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009)[24] acknowledges that community-based options "provide better results for users, their families and the staff while their costs are comparable to those of institutional care if the comparison is made on the basis of comparable needs of residents and comparable quality of care".

In many developed countries the debate has now moved to the issue of which community-based models provide optimal outcomes for people with disabilities. In reviewing the evidence-base on community models, attention should be paid to the considerable variation in outcomes from evaluation of services of the same general type[25]. This variation is likely to reflect the widely differing level of ability of residents. Resident characteristics, however, are not the only source of variation. The design of services[26] and in particular staff performance, is a key determinant of outcome[27]. 'Active support', that is where staff are appropriately trained to provide facilitative assistance to residents, as opposed to completing tasks on their behalf, is an important predictor of quality outcomes for residents[28], [29],[30]. These findings indicate that

[19] Mansell, Beadle-Brown and members of the Special Interest Research Group on Comparative Policy and Practice (2009) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, in press.

[20] Emerson, E., & Hatton, (1994). Moving Out: Relocation from Hospital to Community. London: Her Majesty's Stationary Office.

[21] Kim, S., Larson, SA., & Lakin, KC (2001). Behavioural outcomes of deinstitutionalisation for people with intellectual disability: a review of US studies conducted between 1980 and 1999. Journal of Intellectual & Developmental Disability, 26, 1, 35-50.

[22] Young, L., Sigafoos, J., Suttie, J., Ashman, A., & Grevell, P., (1998). Deinstitutionalisation of persons with intellectual disabilities: A review of Australian studies. Journal of Intellectual & Developmental Disability, 23, 2, 155-170.

[23] Kozma A., Mansell, J & Beadle-Brown, J (submitted) Outcomes of deinstitutionalisation in intellectual disability: a systematic review. American Journal on Mental Retardation. Cited in IASSID (2009) position paper on deinstitutionalisation

[24] European Commission (2009). Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care. Luxembourg: European Commission (p.5)

[25] Mansell, Beadle-Brown and members of the Special Interest Research Group on Comparative Policy and Practice (2009) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, in press.

[26] Felce, D., & Perry, J., (2007). Living with support in the community: factors associated with quality of life outcome. In S. L., Odom, R.H., Horner, M.E., Snell, & J. Blacher (Eds) Handbook of Developmental Disabilities. New York; Guildford Press

[27] Jones, E., Felce, D., Lowe, K., Bowley, C., Pagler, J., Gallagher, B., and Roper, A., (2001). Evaluation of the Dissemination of Active Support Training in Staffed Community Residences. American Journal on Mental Retardation, 106, 4, 344-358.

[28] Felce D., Jones, E., & Lowe, K., (2000). Active Support: Planning daily activities and support for people with severe mental retardation. In S. Holburn & P. Vietze (Eds), Person-centred planning: research, practice and future directions. Baltimore: Paul H Brookes.

[29] Mansell, J, Beadle-Brown, J., & Clegg, S., (2004). The situation of large residential institutions in Europe. In G. Freyhoff, C. Parker, M. Coue, & N. Greig (Eds), Included in Society: Results and recommendations of the European research initiative on community-based residential alternatives for disabled people (pp. 28-56)

[30] Robertson, J, Emerson, E., Hatton, C., Gregory, N., Kessissoglou, S., Hallam, A. et al (2001). Environmental opportunities and supports for exercising self-determination in

community-living is a necessary, but not a sufficient condition for quality outcomes[31]. The provision of appropriate training for staff transferring from congregated to community-based services is an important element in preventing the formation of 'mini-institutions'.

One of the most dominant forms of community-based residential services currently available is the **group home**, providing supports for typically three to eight residents with 24 hour staff supports[32]. NDA consultation with service providers in the US revealed that the maximum number of residents supported within a US group home is typically less than four. Where the number of residents exceeds three, stringent health and safety measures apply[33]. The preference for smaller dwellings across all residential models is reflected in recent data from the US which reveals that 48% of all persons receiving residential services in the US are resident in settings with three or fewer residents[34]. In Australia, the group home model is referred to as 'shared supported accommodation' and typically supports 4-6 residents with rostered staff support[35]. In Ireland, the National Intellectual Disability Database defines a group home as 'a standard domestic-style house in a residential neighbourhood where a small number of people with an intellectual disability live together, with appropriate staff supervision'.

Although the rationale behind the establishment of group homes was to provide a more personalised and integrated residential environment for people with disabilities, there is growing concern and dissatisfaction with this model of support[36]. The commentary of the National Advisory Committee on Health and Disability in New Zealand reflects well these concerns[37] "group homes generally succeed in providing the basics, such as an adequate physical environment, but they are not always able to provide a home. Provision of housing for adults with an intellectual disability has largely focused on providing 'home like' housing. Group homes have therefore had a tendency to become 'mini-institutions'. Although the physical nature of the house may be more appropriate and enjoyable than larger institutions, the daily routine may be very similar". To address these criticisms, the New Zealand Government has made a political commitment to move towards a model of supported living.

In many jurisdictions, the group home model will remain an option for those who are deemed to require 24 hour supports. The general trend, however, is to support residents to move to

community-based residential settings. Research in Developmental Disabilities, 22, 6, 487-502.

[31] Mansell, Beadle-Brown and members of the Special Interest Research Group on Comparative Policy and Practice (2009) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, in press.

[32] Mansell, Beadle-Brown and members of the Special Interest Research Group on Comparative Policy and Practice (2009) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, in press.

[33] National Disability Authority (2008). Exploring Community Living Options for People with Disabilities; NDA Site Visit to USA. Unpublished report.

[34] Lakin, KC., Larson, SA., Salmi, P., & Scott, N (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends through 2008. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

[35] Victorian Auditor-General (2008). Accommodation for People with a Disability. Victorian Government Press.

[36] Mansell, Beadle-Brown and members of the Special Interest Research Group on Comparative Policy and Practice (2009) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, in press.

[37] National Health Committee (2004). To have an 'ordinary' life. Background papers to inform the National Advisory Committee on Health and Disability. National Advisory Committee on Health and Disability. (p.47)

more flexible and individualised alternatives. The experience in Victoria, Australia illustrates the challenges of transitioning from the group home model to more individualised supports. Funding for the group home model has been capped for the last decade while individualised support packages are encouraged[38]. Demand for group homes, however, currently outstrips supply by 30%. A lack of planning for this demand has resulted in a 'crisis-driven system' where residents are temporarily housed in inappropriate accommodation such as hotel rooms or respite[39].

As the group home model is likely to be retained in many jurisdictions for the foreseeable future, the evidence on good practice within these residences is important. In addition to the evidence illustrating the impact of 'active support' on quality outcomes in these settings, evidence also illustrates that quality outcomes are related to the size of the dwelling. Better outcomes are observed for those residing in smaller group homes (1-3 co-residents) than those in larger dwellings (4-6 co-residents). Residents in smaller group homes report less 'depersonalisation', larger social networks, and were considered at less risk of abuse from co-residents than their counterparts in larger group homes[40]. As a residential model, group homes with appropriately trained staff and those which have three or less residents are more positively related to quality outcomes for residents.

Separate accommodation

1.5.5 Family Home

Most people with disabilities registered on the National Intellectual Disability Database and the National Physical and Sensory Disability Database live within the **family home**. Living within the family home does not necessarily, however, equate to full participation in family life. Individuals may be restricted in participating in family activities such as outings, celebrations or holidays for a variety of reasons including their level of ability, the family's economic situation, and the family's attitude of what is considered an appropriate activity. In addition, some families are better resourced and more able to provide or advocate for supports such as recreational pursuits, educational supports and employment options, while others may discourage such activities. People with disabilities, as with other siblings living within the family home, are likely to have to accommodate to family routine. As the individual ages however, family based living may limit the person's ability to exercise choice and control over their lifestyle[41].

In many cases, individuals with disabilities remain in the family home while other siblings have moved out into their own homes. As the individual moves towards adulthood, independence may be hampered by parents who continue to perceive the person as a child. With increasing life expectancy, elderly parents may struggle to provide appropriate care to their son or daughter with a disability while managing their own needs. Age related conditions such as sensory impairment or reduced mobility provide new challenges. Notwithstanding these challenges, it is however the issue of who will take responsibility for the caring role in the future that is of major concern for parents. Unfortunately, findings indicate that older parents receive insufficient information on service options [42]. For many people with disabilities, a lack of

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[38]Disability Services Division (2006) Future directions for housing and support in disability services. Department of Human Services, State Government of Victoria

[39] Victorian Auditor-General (2008). Accommodation for People with a Disability. Victorian Government Press.

[40] Emerson, E., Robertson, J., Gregory, N, Hatton, C., Kessissoglou, S., Hallam, A., Jarbrink, K, Knapp, M., Netten, A., & Walsh, P.N., (2001). Quality and costs of supported living residences and group homes in the United Kingdom. American Journal on Mental Retardation, 106, 5, 401-415

[41] National Health Committee (2004). To have an 'ordinary' life. Background papers to inform the National Advisory Committee on Health and Disability. National Advisory Committee on Health and Disability. www.nhc.health.govt.nz/moh.nsf/indexcm/nhc-ordinary-life

[42] Bigby, C., Webber, R., Bowers, B., & McKenzie-Green, B., (2008). A survey of people with intellectual disabilities living in residential aged care facilities in Victoria. Journal of Intellectual Disability Research, 52,

planning for the future means that leaving the family home is the result of an illness or death of the family carer[43]. Although opportunities exist to discuss future housing options during a young person's transition planning, findings from the UK indicate that parents perceive this issue is rarely addressed during early adulthood[44].

1.5.6 Own Home

Most people with intellectual disabilities do not have the financial resources to purchase their **own home**. In fact, even the upfront costs of a tenancy may be problematic and require advocacy[45]. For some families, **private trusts** may be considered. These trusts comprise accommodation purchased by family members with staff support. In some cases, the accommodation may in fact be the family home, with parents moving out to alternative accommodation. This arrangement gives family members a considerable level of control regarding the accommodation and staffing arrangements. Given the likely cost of establishing and maintaining such an arrangement, however, it is unlikely that this form of residential support is a viable option for many families.

1.5.7 Shared Living Arrangements

A growing model of home-based residential supports within the US is the **Shared Living Arrangement**. The arrangement is facilitated by a service provider between an individual with a disability who wishes to live within a private home and a host family. Contracts between both parties usually specify that the host family is obliged to participate in a vetting process, a home inspection, mandatory in-service training and is required to attend ongoing consultations and team meetings with the service provider. The contract may also include a sub-contractual agreement for day service provision. The host family receives an annual tax free stipend of approximately $25,000 to support the individual[46]. In the event of difficulties between parties, a 24 hour on-call crisis response team is available with a range of supports including the option of emergency respite. In addition, host families receive an annual allocation of respite to be used at their discretion.

This model initially emerged as a preferred option for many staff and residents following the closure of large state-run institutionalised settings. These shared living arrangements are now more formalised and, while not typical in Ireland, are available in other jurisdictions. New Zealand's 'Contract Board' model, for example, is a variation of this type of support. Within the US, a total of 38,262 persons with intellectual and developmental disabilities were supported through this model in 2008, comprising 8.8% of all those in receipt of residential services[47]. While this model is not typically available throughout Ireland, small scale projects are being piloted. The Brothers of Charity in Galway and Ability West, for example, have enrolled host families to provide 16 nights of respite per month for adults with disabilities. The typical remuneration per annum for this support is €8,000. The project, funded by Pobal runs for two years[48]. Similarly, the Brothers of Charity, Clare provide a Home Share service where people with disabilities reside with host families on a part-time basis.

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[43] Department of Health (2001). Valuing People: A new strategy for learning disability for the 21st Century. Department of Health; London

[44] Heslop, P (2002). Bridging the divide at transition: What happens for young people with learning difficulties and their families? British Institute of Learning Disabilities, UK.

[45] National Health Committee (2004). To have an 'ordinary' life. Background papers to inform the National Advisory Committee on Health and Disability. National Advisory Committee on Health and Disability. www.nhc.health.govt.nz/moh.nsf/indexcm/nhc-ordinary-life

[46] National Disability Authority (2008). Exploring Community Living Options for People with Disabilities; NDA Site Visit to USA. Unpublished report.

[47] Lakin, KC., Larson, SA., Salmi, P., & Scott, N (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends through 2008. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

[48] Daly, C & Byrne, C., (2009). Contract Families: A new future for family and community living in Ireland. Frontline, 77, 13-14.

1.5.8 Supported Living

Of the various 'separate accommodation' models available to people with disabilities, **supported living** is dominating. While variously defined, supported living refers to people with disabilities living with individuals they choose, in their own housing, as either a home owner or more typically a tenant, while receiving domiciliary care support from service providers who are not involved in the provision of their housing[49].

Within the UK, where supported living is endorsed by Government policy[50], supported living properties are typically owned by housing associations who provide both the property and housing management services under an assured tenancy. Through contractual agreements with funding bodies, such as grants accessed to build the property and local authority grants to provide services, the property is classified as a residential property for supported living. The residence can therefore only be used to support tenants as per the specification of the tenancy[51]. Depending on the level of need of tenants, supports from domiciliary care staff may range from 24 hour on-site support to drop-in floating support. Supported living can be provided in single or shared dwellings. Where dwellings are shared, the maximum number of tenants is usually four.

While there is an acknowledgement that supported living is a new model and has yet to be comprehensively evaluated, the limited studies that are available suggest that supported living provides greater opportunities for choice and community participation[52], [53] and is more economical given the lower staffing costs[54]. People in supported living arrangements were found to have more friends outside the home, were more likely to be known by their neighbours, and to receive visitors[55], [56]. In comparison with their peers in clustered settings, people in supported living were found to be six times more likely to use community resources[57].

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[49] Mansell, Beadle-Brown and members of the Special Interest Research Group on Comparative Policy and Practice (2009) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, in press.

[50] Department of Health (2009) Valuing people now: a new three year strategy for people with learning disabilities. London HM Government

[51] Domiciliary Care Agencies provide similar supports to those outlined above to tenants and home owners who are living in residences that are not designated as 'supported living properties'. Older persons living in their own homes and people with intellectual disabilities living in the family home, for example, may benefit from these services. These supports are not defined as 'supported living' arrangements but rather as 'sessional' or 'domiciliary care' supports.

[52] Emerson E, Roberston J, Gregory N, Hatton C, Kessissoglou S, Hallam A, Jarbrink K, Knapp M, Netten A, & Walsh PN., (2001). Quality and costs of supported living residences and group homes in the United Kingdom. American Journal on Mental Retardation, 106, 5, 401-15.

[53] Howe J, Horner RH, & Newton JS, (1998). Comparison of supported living and traditional residential services in the state of Oregon. Mental Retardation, 36, 1, 1-11

[54] Stancliffe, R., & Keane, S., (2000). Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. Journal of Intellectual & Developmental Disability, 25 (4) 281-305.

[55] Emerson, E., & McVilly, K., (2004). Friendship activities of adults with intellectual disabilities in supported accommodation in Northern England. Journal of Applied Research in Intellectual Disabilities, 17, 3, 191-197

[56] Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P, Cambridge, P, Tate, A., Beecham, J., et al., (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. Journal of Applied Research in Intellectual Disabilities, 19, 4, 285-295

[57] McConkey, R., Abbott, S., Walsh, PN., Linehan, C., & Emerson, E., (2007). Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. Journal of Intellectual Disability Research, 51, 3, 207-217.

'Smart home technology' enables tenants to live in their own property with minimal staff supports. This technology will alert support staff in the event of a fall, seizure, etc. The technology fulfils a 'just in case' role, where previously support staff were required particularly at night, 'just in case' the tenant required emergency support. These types of innovations are a major contributor to the lower staffing levels in supported living accommodation, and this in turn is associated with greater positive outcomes for residents[58]. Professor David Felce, an authority on residential supports for people with disabilities concludes "put simply, people living with only partial staff support appear to conduct their lives more independently than do people living with constant staff support. This is not due to differences in their independent capability but to the inhibiting effect of staff presence".

There are however some disadvantages to supported living arrangements. The flexibility of the model may result in persons being inadequately supported in the community and being exposed to risk[59]; establishing and maintaining social relationships may be difficult; and coordinating funding from independent sources may be problematic. An examination of independent living supports in Ireland[60] noted that "although there are some comprehensive support packages in place, supports for independent living are under-resourced. There is also a lack of clarity about entitlements and options arising from different models of delivery in different parts of the state". Clarity is also required as to whether current national quality standards developed by HIQA for 'designated' residential services for people with disabilities apply to independent living arrangements[61]. A quality assurance framework, with agreed standards and a monitoring system, will be required to assure the quality of such services.

Despite these challenges, supported living can meet the aspirations of people with disabilities. The Inclusive Research Network, a group of Irish self-advocates with intellectual disabilities report that respondents to their survey on residential provision call for more control and choice regarding where, and with whom they live. Their research reflects well the UK Government policy to support the 'personalisation' agenda[62].

The development of supported living options is linked with arrangements to give control of funding to the person with a disability or their advocate to purchase their own supports directly[63] via direct payments or individualised budgets. These **self-directed supports** represent a major paradigm shift whereby people with disabilities are the purchasers of their own supports. Direct payments are typically used to support the individual to engage in community activities and, in the UK, cannot currently be used to purchase permanent residential care, local authority provision or health care. While the model is, as yet, untested in the long term, it is high on the UK Central Government agenda. Self-directed options are promoted by the UK Government's 'In Control'[64] programme which aims to restructure the

[58] Felce D, Perry J, Romeo R, Meek A, Robertson J, Emerson E, Knapp M. (2008) Outcomes and costs of community living: Semi-independent living and fully staffed group homes. American Journal on Mental Retardation, 113, 87-101. (p.98)

[59] Emerson E, Roberston J, Gregory N, Hatton C, Kessissoglou S, Hallam A, Jarbrink K, Knapp M, Netten A, & Walsh PN., (2001). Quality and costs of supported living residences and group homes in the United Kingdom. American Journal on Mental Retardation, 106, 5, 401-15.

[60] Citizens Advice Board & Disability Federation of Ireland (2007). The Right Living Space: Housing and accommodation needs of people with disabilities. Citizens Advice Board & Disability Federation of Ireland (p.57)

[61] http://www.hiqa.ie/media/pdfs/National_Quality_Standards_Residential_Services_People_with_Disabilities.pdf Retrieved 19 February 2010

[62] Department of Health (1993). Services for people with learning disabilities and challenging behaviour or mental health needs. London: HMSO.

[63] Mansell, Beadle-Brown and members of the Special Interest Research Group on Comparative Policy and Practice (2009) Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, in press.

[64] www.in-control.org.uk

organisation of social care in the UK by placing people with disabilities as the commissioners of their own supports. Undoubtedly, this shift towards self-directed supports will have a significant impact on service providers who will need to react appropriately to the change in commissioning roles.

1.6 Conclusion

This brief review has attempted to outline some of the more typical residential options available to people with disabilities in Ireland and internationally. The options are presented on a continuum from large congregated settings to individualised supports. In addition, the options are classified as either 'comprehensive placements' or 'separate accommodation'. While the scope of the review is clearly limited, a consistent pattern emerges. Smaller, community-based dwellings that provide opportunities for choice and control are associated with greater quality outcomes for people with disabilities. The trend towards self-directed supported living is increasingly gaining momentum and is likely to continue given its alignment with the vision of personalisation and choice advocated by the UN Convention on the Rights of People with Disabilities.

Although supported living is the current model of choice, many people with disabilities reside in other models of support. The group home model in particular is the dominant model in many jurisdictions. As a community-based model, the group home is evidenced to be preferable to large congregated settings. Being placed in the community however, while a necessary condition for community participation, is not a sufficient condition. Residents' level of ability and the training of staff in active support methods are key mediators of quality. Where comprehensive placements are provided, they should remain small and ensure that staff are appropriately trained.

Current trends suggest that separate accommodation options, such as living within the family home, shared living arrangements and supported living will become the dominant models. The development of these models however goes beyond the bricks and mortar of housing. Self-directed supports are emerging as the preferred mechanism for the arrangements of supports. It is timely for those who commission, monitor and provide supports to consider the implications of self-directed support for the future development of disability services.