Variations in residential accommodation for adults with intellectual disabilities: the example from Northern Ireland

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# Introduction

- People with moderate and severe forms of ID often require lifelong care and internationally and in Ireland this is mostly provided by the persons parents (Barron et al 2005)
- In Great Britain and N. Ireland for most of the 20<sup>th</sup> century the main form of provision was long-stay hospitals (Felce, 1996)
- The concept of smaller group homes located in ordinary domestic housing emerged from 1980s onwards and was promoted by voluntary organisations (Towell, 1988)
- This has become the dominant model of provision in the Republic of Ireland (Barron & Mulvany 2003)
- Another form of provision –village or intentional communities e.g., Camphill Movement emerged in the 1950s (Bock, 2004)
- In recent years the concept of 'supported living' has emerged

# Supported living

People with intellectual disabilities hold the tenancy to their own home on either an individual of shared basis (2 or 3 others) support staff visit the home to assist the person with personal care, household tasks and community access. This can extend from a few hours a day to staff staying overnight on a rota basis. This model is best developed in Scandinavian countries with examples common in US and Australia (Braddock et al 2001)

# Method

- Phase1: estimating numbers of people was done via five data sources
- Phase 2:information on individuals collected on a pro forma and included background information about residence, length of time person was resident, where they had lived previously, number of people dwelling in same residence, whether person shared a bedroom, gender, ethnicity
- Respondents were also asked to rate each person on five dimensions related to their care level of dependency in personal care, supervision required, activity levels, nursing care, vulnerability to abuse.
- 3-4 point scale covered concepts of high medium and low needs

# Response rate

- Information was obtained on 94% of hospital patients
- 86% of people in all types of residential facilities

## Results

- 1,920 persons aged 20 years and over were identified as living in some form of residential accommodation in N. Ireland
- Around 440 persons in specialist hospitals
- This is less than 1/3 of the total estimated population of adult persons with ID in N. Ireland in 2003 (McConkey et al 2006)

# Results

- Type of accommodation provided
- Previous abode
- The management of the service
- Characteristics of the person in the various accommodation options

# Type of accommodation provided

Option	Total Northern Ireland	Total Northern Ireland %		
Nursing Home	574	24		
Specialist Hospital	440	18.2		
Residential Home	436	18.3		
Shared Home	402	16.9		
Dispersed Supported	222	9.3		
Living				
<b>Clustered Supported</b>	120	5.0		
Living				
Village community	130	5.5		
Small group homes	87	3.6		
Total	2411	100		

- adapted from McConkey (2006)
- \*\* included 42 persons dually registered

# Summary

- Nearly ¼ of persons were resident in nursing home accommodation
- Median number of residents in nursing homes was 28 persons (range 7-54). As many as 92 persons on the same site
- Estimated 440 persons remained in three specialists hospitals at time of study. Most accommodation in the from of multioccupancy wards total number of patients on same site ranged from 52 -300 +
- Next most common form of accommodation was residential and shared homes
- In shared homes median number 12 persons (range 1-22) up to 34 living on the same site
- In residential homes median was 15 (range 3-36)
- In group homes median was 3 people (range 2-6) but up to 34 on same site
- Around 14% in the form of supported living median number in dispersed and clustered arrangements was 2 per dwelling (range 1-4) 17 was the highest number of tenants on same site.
- Village communities median of 5 persons in the same house (range1-9) with up to 95 people (includes staff) on the same site

# Number and percentage of places in each size of residential accommodation

Size	Total Northern Ireland	Total Northern Ireland %	
1-6 persons	593	30.1	
7-15 persons	582	29.5	
16 and over persons	796	40.4	
	1971	100	

- adapted from McConkey (2006)
- does not include figures from specialized hospitals n=440

# Length of time

- Varied from a few months to over 50 years-(median of 7 years)
- Those living in village communities had resided there longest (median 10.5 years)
- Nursing homes (median 9 years)
- Residential and shared homes (median 7 years)
- Supported accommodation (median 5 years)
- Hospitals (median 24 years)

# Previous abode

- 42% of persons in residential accommodation had previously lived in hospital
- 25% had previously lived in other residential accommodation
- 32% had come from previously living with family carers

### Management of residential care

- Almost half of residential provision was provided by private sector organisations (46.7%)
- 22% provided by voluntary agencies
- 21.3% provided by statutory sector
- 10.3% by housing associations

### Management of residential care

- Private sector provisions took the form of nursing and residential care homes with 95% of these places in settings for 7 or more persons (median of 20 persons per dwelling; range 3-54)
- Voluntary agencies provided all options except nursing homes
- Shared housing and village communities the most common (median no. of people in same dwelling 6.5 persons (range 3-54)
- Statutory provision was in the form of residential or shared housing and dispersed supported living median number of person per dwelling was 3 (range 1-20)
- Hosing associations offered mainly shared housing (formerly registered accommodation) and clustered supported living; median of 10 persons per dwelling (range 1-16) or 13 persons per site (range 4-17)

### Management of residential care

- All tenants of housing accommodations had their own bedroom but his was not so with other providers
- 85% with statutory agencies
- 80% with voluntary agencies
- 77% in private homes

Characteristics of persons in residential accommodation

- **54%** male; 46% female
- More males resident in hospitals, village communities and nursing homes
- Fewer males in residential homes and supported living
- Median age was 48 years (range 20-95)
- Those in village communities sig. younger than those in hospitals who in turn were younger than those in other settings

# Characteristics of persons in residential accommodation

- People living in hospital and nursing homes were more likely to be rated as highly dependent in their personal care compared to those in residential homes, supported living and village communities
- Those living in nursing homes required more nursing care than those in hospitals
- Those in hospitals were rated as needing extra supervision
- Hospital patients were more likely to be perceived as having a higher risk of abusing others compared to residents in all other settings
- Also to have a higher risk of engaging in offending behaviours
- Hospital patients present with a different range of characteristics than those in all other settings
- Those in nursing homes also require more personal and nursing care

### Discussion

- The proportion of people living in long-stay hospitals is higher in N. Ireland than elsewhere in the UK
- Common explanation is the lack of a concerted resettlement programme with allied funding
- Main alternative to hospital beds has been the provision of nursing and residential homes
- Proportion of people living in nursing homes in N. Ireland is sig. higher than that reported for England (this is however balanced by increased residential home provision there)
- Less than 1/3 of persons in N. Ireland live in accommodation for no more than 6 persons comparable percentage in the US is 51% and 90% or more in Scandinavia)
- Greater investment is required to make this shift

# Discussion

- Limited evidence that accommodation is provided according to an individuals need
- People in residential homes, shared homes supported living and village communities had broadly similar characteristics although the nature of accommodation provided varied
- One area of concern is the low number of people who previously lived in the family home highlights the dearth of opportunities open to families for their relative to move into residential accommodation away from the family
- Places undue stress on elderly family carers and may result in emergency placements that are not suitable for the person

### Discussion

- Important baseline data from this study on accommodation options at one point in time
- A repeat in 5 or ten years time would help monitor the impact of new policy initiatives

# Ireland



#### Information has been taken from the Annual Report of the NIDD 2007

#### HRB Statistics Series 2 Annual Report of the National Intellectual Disability Database Committee 2007

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Disability Database Unit Health Research Board



improving people's kealth through research and information

### Annual Report of the NIDD 2007 main residential circumstances

#### All levels

	0-19	20-34	34-54	55+	Total
Home setting	8586	4536	2768	476	16366
Independent Setting	7	180	515	201	903
Community group home	129	807	2000	814	3750
Residential Centre	95	588	1530	965	3178
Other full-time services	62	366	540	366	1334
No fixed abode	0	4	6	3	13
Insufficient Information	7	15	28	19	69
Total	8886	6496	7387	2844	25613

#### Non-verified

	0-19	20-34	34-54	55+	Total
	1000	1.7.5	1.70		
Home setting	1922	156	159	45	2282
Independent Setting	0	14	51	29	94
Community group	3	9	24	9	45
home					
<b>Residential Centre</b>	5	9	22	47	83
Other full-time	9	3	10	25	47
services					
No fixed abode	0	1	0	1	2
Insufficient	3	0	0	0	3
Information					
Total	1942	192	266	156	2556

#### Mild

0-19	20-34	34-54	55+	Total			
3362	1766	1050	173	6351			
4	135	376	124	639			
34	171	411	234	850			
6	38	93	110	247			
3	52	81	82	218			
0	2	4	1	7			
2	6	0	0	8			
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Moderate, Severe and Frotound						
	0-19	20-34	34-54	55+	Total	
Home setting	3302	2614	1559	258	7733	
Independent Setting	3	31	88	48	170	
Community group home	92	627	1565	571	2855	
Residential Centre	84	541	1415	808	2848	
Other full-time services	50	311	449	259	1069	
No fixed abode	0	1	2	1	4	
Insufficient Information	2	9	28	19	58	
Total	3533	4134	5106	1964	14737	
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- 16,366 (63.9%) live in a home setting with parents relatives or foster parents
- 8,262 individuals (32.3%) live in full-time residential services mainly in community homes, residential centres, psychiatric hospitals and intensive placements
- 903(3.5%) live independently or semiindependently

- The most commonly availed of residential settings are group homes. More people live in group homes in the community (3,750) than in residential centres (3,178)
- 387 people reside in full-time mental health services psychiatric hospitals (n=329) or mental health community facilities (n=58)
- 13 individuals have no fixed abode

- One in four people with a moderate severe or profound ID aged 35 years or over continue to live at home
- Planning for the future and for crisis situations is vital
- 15.8% of people with mild ID live in full-time residential services
- 46% in the case of those with moderate, severe or profound ID

- Full-time residents with mild ID are most likely to be accommodated in community homes (64.4%)
- Full time residents with moderate, severe or profound ID are most likely to be accommodated in residential centres