

# Patterns of service use among people with learning disabilities discharged from long-stay hospital care in Northern Ireland

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## Abstract

**Objectives:** Continuing deinstitutionalisation has led to growing concern about the availability and accessibility of services for people with learning disabilities transferring to community living. This study was undertaken in order to assess the configuration of services in terms of availability and uptake for people with learning disabilities who have left long-stay hospital care and to identify gaps or barriers to service provision within the unique integrated health and social services structure in Northern Ireland.

**Method:** The 'keyworkers' of 195 people – most of whom were aged 40-59 years with a diagnosis of moderate intellectual impairment – were interviewed by a researcher one year after discharge using the Service Interview.

**Results:** While a wide range of generic and specialist services was available, 'packages' of care consisted largely of public sector services (eg. GPs, chiropodists and social workers) and relied, to some extent, on the type of community accommodation. Although services appeared well co-ordinated in terms of care reviews and keyworker arrangements, 40% of people required more one-to-one support particularly in areas related to integration. However, services were perceived by care staff to be satisfactory

**Conclusions:** The development of community care has been slower in Northern Ireland than elsewhere and a large proportion of resources remain tied up in hospital care. However, existing community-based services appear to be addressing individual needs. Some former patients, though, may have been subject to transinstitutionalisation in the sense that their choice of community accommodation was restricted mainly to large private sector homes and work and daytime opportunities were insufficient to facilitate integration. Service planners and providers need to give further consideration to the likely effects of different forms of rehabilitation, reprovision and resettlement and to be aware that the pattern of service provision is likely to be different for the more dependent cohorts of people who leave hospital in the future.

**Keywords:** Learning disability; Community care; Long-stay hospital.

## Introduction

Service availability and accessibility have become issues of growing concern with the continuing implementation of

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the discharge policy, but only a small number of studies have examined service provision for former hospital residents with learning disabilities.<sup>1</sup>

The relocation from long-stay hospital care to the community may lead to transitory behavioural problems and other forms of transfer trauma in people with learning disabilities.<sup>2,3</sup> It is important, therefore, that comprehensive and well co-ordinated services are available following discharge. Northern Ireland has an integrated health and social services structure administered by the Department of Health and Social Services (DHSS) via four HSS boards and 20 HSS trusts. In its 1987-1992 regional strategy, the DHSS set specific targets of a 20% reduction in the numbers of people in long-stay learning disability hospitals.<sup>4</sup> 'Bridging' funds totalling approximately £34 million over six years were allocated to the four health and social services boards to assist in developing appropriate forms of community care (for both psychiatric and learning disability populations).

Although this goal was successfully achieved, little was known about former patients or their use of services. In 1991, the DHSS<sup>5</sup> proposed a further reduction of 30% in the long-stay hospital population by 1997, and more recently advocated the development of "a comprehensive range of supportive services for people with a learning disability and their carers, the aim being to reduce to zero by 2002 the number of long-stay patients in hospital".<sup>6</sup>

However, the rate of hospital retraction in Northern Ireland has for some time lagged considerably behind the rest of the UK (44% of hospital places open in England in 1980 were still open in 1992 compared to 70% in Northern Ireland). Consequently, the three learning disability hospitals in Northern Ireland are providing accommodation and care for a total of 533 long-stay inpatients. It is also important to note that, according to a review of services for people with learning disability in Northern Ireland, approximately 90% (7,455/8,258) (in 1993) live in the community.

The aims of this study were to:

- outline the background characteristics and community destinations of people with learning disabilities one year after discharge
- describe patterns of service use including the staff-perceived availability, accessibility and appropriateness of services.

The study was undertaken as part of a larger evaluation of community care for 497 people discharged during 1987-1992 from the three learning disability hospitals in Northern Ireland. This paper focuses on those discharged between 1990 and 1992 (see Donnelly *et al*<sup>7</sup> for details of the study background and former patients).

## Method

The Service Interview (SI)<sup>8</sup> was used to collect informa-

Table 1: Receipt of services by type of community accommodation

Type of accommodation	Percentage of people receiving services*											
	GP	CHIR	DENT	SW	CONS	OPTIC	OTHER	CMHN	OT	PHYS	PSYC	DN
<b>Private</b>												
Nursing home** (n = 22)	67	56	55	46	21	22	13	3	12	7	2	2
Residential home (n = 21)	78	61	61	22	17	-	22	22	-	-	-	6
<b>Public</b>												
Hostel/Residential home (n = 28)	87	71	77	58	19	23	29	10	10	6	3	3
<b>Voluntary</b>												
Hostel/Residential home (n = 22)	86	62	62	57	52	38	10	38	-	5	-	-
Living with the family*** (n = 4)	50	-	100	50	-	-	-	50	-	50	-	-
<b>Total (n = 197)</b>	<b>73</b>	<b>63</b>	<b>60</b>	<b>47</b>	<b>23</b>	<b>22</b>	<b>6</b>	<b>12</b>	<b>9</b>	<b>5</b>	<b>2</b>	<b>2</b>

\*GP = General practitioner; CHIR = Chiropodist; SW = Social worker; DENT = Dentist; CONS = Consultant psychiatrist; OPTIC = Optician; OTHER = Mainly speech therapists, but also dietitians; CMHN = Community mental handicap nurse; OT = Occupational therapist; PHYS = Physiotherapist; PSYC = Psychologist; DN = District nurse.

\*\*Two people living in private nursing homes had an SI completed at the 12 month follow-up just before re-admission to hospital. \*\*\* One person living with family did not have an SI completed.

tion from care staff about the services received by each former hospital resident during the period between six and 12 months after discharge. This six-month period was chosen, firstly, because it reflected a longer term picture (ie. service provision during the first six months after discharge might not be typical) and, secondly, because services received during this time could be more easily recalled at the one-year follow-up. The SI is completed by a researcher in conjunction with a 'keyworker' or other care professional (eg. a staff nurse). Information was collected for all those still living in the community at the one year follow-up and for one person who was re-admitted to hospital just before the one-year follow-up was due (n = 197).

The data are based on:

- contact with approximately 25 services
- frequency and duration of service use
- whether or not the service was provided at home or elsewhere.

Interviewees were also asked to rate broadly (on a scale from one (high) to three (low)) their level of satisfaction with the availability/accessibility of services (eg. 'usually sufficient') and their quality/appropriateness (eg. usually 'helpful/appropriate'). Unmet need, gaps in service provision (eg. poor communication between staff) and other relevant care staff inputs (eg. care review meetings) were also recorded in order to assess the extent to which services were tailored to individual need.

## Results

### Background characteristics and community destinations

A total of 214 people left hospital between April 1990 and June 1992. The majority at each hospital were males aged between 40 and 59 years who had spent over 20 years in hospital and who had a moderate degree of intellectual impairment (which for the purposes of this study refers to people with IQ scores of between 20 and 49). Characteristics were summarised along several dimensions by year of discharge; for example, 55% of the 131 people who left hospital in 1991 were male; 47% (61/131) were aged 40-59 years while 25% (33/131) were aged 60-89;

59% (77/131) had spent more than 20 years in hospital compared to 21% (28/131) with a length of stay of less than 10 years; and 63% (82/131) had moderate levels of intellectual disability compared to 20% (26/131) with high levels of ability. Almost two-thirds of the entire group were discharged to private nursing homes (ie. typically large privately-owned settings of 20 places or more). The remainder were relocated to private (12%, 25/214) or voluntary sector (10%, 22/214) residential homes and to public (ie. DHSS owned) hostels or group homes (13%, 28/214). Only five people (2%) returned home to their families. Ninety-one per cent (196/214) were still living in the community after 12 months while six per cent (14/214) had been re-admitted to hospital owing mainly to behavioural problems such as aggression. Four people (2%) had died – two from pneumonia and two from cancer.

### Use of core services

The five services most commonly used by the 197 people for whom information was available included general practitioners (GP), chiropodists, social workers, dentists and consultant (learning disability) psychiatrists respectively (Table 1). Two-thirds (95/144) of those who had seen a GP had up to three contacts in the six-month period, 41% of which were domiciliary (home) visits. Twenty per cent fewer private nursing home residents than in voluntary or public settings had seen a GP (Table 1). Sixty-three per cent (124/197) of people had seen a chiropodist during the previous six months, most of whom were public sector residents. Those living with their families had no contact with chiropody services.

Social workers were the third most commonly used service (60%, 119/197) and were seen *regularly* (ie. at least once a month) by almost one quarter of people. All four people living with their families had also seen a social worker while the same was true for over 75% of public sector residents (Table 1). However, fewer people living in private nursing homes than elsewhere had received this service. Almost half (93/197) had also received dental care, 87% of whom had seen a dentist at least twice in the previous six months. Private residential home residents were

least likely to have received this service. Almost 25% (46/197) had seen a consultant psychiatrist during the previous six-months including 37% more people from settings run by the voluntary sector than private or public accommodation (Table 1).

*Staff-perceived availability and appropriateness of 'core' services*

Very few services were rated by care staff as unsatisfactory. Unmet need was indicated in only two cases – for chiropody and consultant care – while barriers to service provision (eg. 'poor review of client needs') were noted for three people who were seeing a social worker. Otherwise, all five services were rated as satisfactory.

*Other care staff inputs*

All 197 people had received one-to-one support (two hours per week, on average), two-thirds of whom (130/197) had received more than eight hours a week. However, 40% (79/197) were judged to require more support of this kind particularly in areas related to social skills development. Ninety per cent had a designated keyworker and care review meetings had been organised for 78% (153/197) of people, most of which (122/153) had taken place bimonthly and had involved some form of care planning, service packaging, monitoring or reassessment (73%, 112/153). At least one professional (usually a social worker) had attended 73% of meetings, two had been present in almost half and three had attended 29% of meetings. Social workers, psychiatrists and GPs were most likely to be involved in care reviews.

The majority of people had *not* used hospital services during the previous six months. For example, six people (3%) had been re-admitted briefly to a learning disability hospital. However, a quarter of the group had visited a general hospital, 15% (30/197) of whom had attended an outpatient clinic and 9% (17/197) of whom had received general hospital inpatient care.

*Day services, work and daytime activities*

Almost half of the group were attending clubs while 27% were visiting a day centre on a regular basis (see Table 3). However, participation in open or sheltered employment settings was very limited. Furthermore, 81% (51/63) of those involved in 'work' were participating in work activities available in social education or adult training centres. While structured and work-related day care activities were all provided off-site, sizeable proportions of people were involved in other daytime and recreational activities such as shopping and outings which tend to be organised on a group-basis (Table 3). Furthermore, 43% (85/197) of people had visited friends/relatives on at least one occasion during the previous six months.

*Service 'packages'*

Former patients had received an average of five services. Thirty-seven per cent (73/197) had received three or fewer services while the same proportion had been in contact with six or more different services. It was difficult to determine broad trends by sector owing to the predominance of private sector accommodation. Nonetheless, 47% (58/122) of private nursing home residents had received fewer than four services compared to only 29% of those in private residential (6/21) and public sector accommodation (8/28) and 14% (3/22) in voluntary settings. A

Table 2: Other care staff inputs

Care staff input (for previous 6 months)	No. of people (n = 197)	%
In receipt of direct one-to-one support	197	100
In need of more one-to-one support*	79	40
Had a nominated keyworker**	179	90
CPN/Staff Nurse	63	35
Nursing/Care Assistant	97	54
Social Worker/Project Worker	2	1
Direct meetings with keyworker which took place at least once a week	66	37
Care review meetings arranged for client	153	78

\*Most were in need of social skills training or diversional therapy and needed no more than seven additional hours of individual support.

\*\*The keyworkers for a small proportion of residents were residential workers and officers-in-charge or accommodation managers.

Table 3: Daytime, work and social activities

Type of activity during previous 6 months	No. of people (n = 197)	%
<b>Day Centres</b>		
Total attending	53	27
Mental health resource centre	6	11
Social education centre (SEC)	36	68
Generic day centre	8	15
Type not known	3	6
At least one weekly visit	51	96
<b>Clubs</b>		
Total attending	92	46
At least one weekly visit	70	76
<b>Work</b>		
Total Involved in 'work' activities	63	32
Open employment	1	1
Sheltered employment	-	-
SEC/adult training centre	51	26
Workshop	11	5
<b>Other</b>		
Weekly shopping	120	61
Made at least one social visit	85	43
Been on day trips or outings	157	70
Been to cinema/theatre	34	23
Engaged in sport	58	29
Involved in any other social activity (eg. eating out)	44	22

cost-effectiveness analysis – conducted in the larger evaluation – suggested that services were responding to people's needs; for example, those with more serious cognitive impairments and disturbed sleep patterns were receiving more costly community care packages.

**Discussion**

For most of the people in this study, care outside hospital encompasses the use of facilities which are very different from the small-scale 'domestic' environments envisaged in the 'ordinary life in the community' policies

in the UK (eg. The All Wales Strategy<sup>10</sup>). The provision of day services and work activities, in particular, is important for the successful adaptation to community living for people with learning disabilities. According to our keyworkers, there may be some unmet need for structured day care and work activities despite the large proportion of people involved in daytime activities. The ways in which day care resources are used is critical to the process of normalisation'. However, at the time of this study (1993) service providers did not appear to be moving away from the conventional ways of organising and delivering services. These findings are similar to a number of English studies<sup>11-13</sup> in which access to day care, meaningful occupation and employment were identified as areas of concern for former hospital residents with learning disabilities.

The people in our study were similar to those in the English Care in the Community Demonstration Programme<sup>14</sup> on which the current study was modelled. GPs, as in the English study, played a central role in providing routine medical care. The consultation rate is approximately twice the UK average of 3.8 per annum. Over 75% (54/197) were also receiving regular medication mainly for physical illnesses and this may explain, in part, the high level of GP contact. However, it is equally plausible that keyworkers and GPs were responding in a proactive way towards this client group in the first year after discharge. Future work should examine why so many former hospital residents need to see a GP and whether or not GPs require support in order to provide appropriate care. The findings also raise questions about the adequate resourcing and support of future possibly more dependent cohorts of hospital leavers

Unfortunately, no information was available from this study on those who had died (2%) or been re-admitted to hospital (6%). It is possible that small numbers of people may have experienced translocation shock after discharge leading to a deterioration in their physical health or overall behaviour. For example, research has shown that discharge from hospital may have negative consequences in the short-term for a minority of vulnerable people.<sup>2</sup>

The input from social workers in this study was greater than in the Care in the Community Demonstration Programme.<sup>14</sup> Proportionately more people in public provision had seen a social worker reflecting the routine delivery of social services in Northern Ireland to public sector residents. The frequent contact with social workers, GPs and chiropodists suggests that a reasonably high level of care was sustained beyond the critical first six months after discharge. Chiropody and dental services tended to be provided to *groups* of residents in the same home but while this institutionalised 'en-bloc' delivery<sup>15</sup> may be a practical care arrangement, it might also be counter-productive in terms of achieving the goals of normalisation or in leading to over-provision. Both services were also commonly used in the study by Knapp et al<sup>14</sup> although about 20% more people in our study (63%) – most of whom had generally poor self-care skills – had seen a chiropodist.

The typically high level of staffing in private nursing homes may account for the relatively low use of community mental handicap nurses (CMHNs) (see Table 1), although only 36% of staff in nursing homes in Northern Ireland are qualified.<sup>16</sup> In addition, many people with learning disabilities are now receiving care in a system dominated by professionals who also provide care to other

client groups.<sup>17</sup> However, the limited role of physiotherapists, occupational therapists (OT) and speech therapists (see Table 1) may be a cause for concern as these services can often be crucial in developing 'ordinary life' skills.<sup>18</sup>

There was some variation in service utilisation by type of accommodation despite the predominance of private sector homes. Patterns of service utilisation were dominated by services most likely to be used by the care settings to which people were discharged. For example, voluntary sector residents were most likely to be in contact with CMHNs and community-based consultants. They were also more likely to be receiving a larger number of services than people living elsewhere, most probably because of a lower level of professional staffing. On the whole, private sector residents were least likely to be 'high' service users. This may be due to the generally higher staffing levels or it may reflect an inappropriately low level of contact between privately run settings and public service providers. However, it is not clear to what extent these patterns reflect individual ability or better service delivery for public or voluntary sector residents. Furthermore, research has shown that there need not be a link between higher staffing levels and staff-resident interaction or resident participation in daily living activities. In addition, the unique integrated health and social services structure in Northern Ireland tends to facilitate the routine delivery of services to people under public sector care.

Staff-perceived quality and appropriateness of services were rated as satisfactory while unmet need for care was rarely indicated. This suggests that an adequate range of services was perceived to be available and that everyone had received regular one-to-one support. While these data are based on information provided by keyworkers rather than on detailed assessments, the professionals had a detailed knowledge of the services received by the residents to whom they were assigned and also had access to their personal records. This information is validated, in part, by findings from a survey of users' views in the larger evaluation<sup>7</sup> which – though not *directly* related to service use – indicated that people were more satisfied with life in the community than in hospital. While the needs of some people particularly in areas related to integration were not being fully met, information on care review and keyworker arrangements suggests a reasonable degree of service co-ordination and frequent, proactive professional involvement.

The development of a mixed economy of care for people with learning disabilities in Northern Ireland – in contrast to elsewhere in the UK<sup>17</sup> – was limited in that most of the accommodation comprised large highly staffed private sector homes in which contact with the community was minimal. Furthermore, the findings from the larger evaluation showed that 27% of people were living in 'institutional' settings and that there were few dramatic changes in level of functioning or quality of life for the group as a whole. Arguably, therefore, few of these people would appear to have made a *significant* 'transitional step' in their lives. This raises the possibility that some people were subject to a process of transinstitutionalisation. Evidence from the UK<sup>20</sup> suggests that community settings which provide richer and more intensive ranges of care packages tend to produce better outcomes. Therefore, it is possible that improvements in care packages for Northern Ireland residents could lead to greater outcomes particularly for people in private sector facilities.

However, it is also important to note that the financial arrangements underlying private residential or nursing home care before the implementation of the community care reforms in 1993 may have prevented access to community-based services and, to some extent, the development of alternative types of accommodation.<sup>9</sup> Substantial sums of money (£65 million during 1993-1995) have since been transferred from the social security budget to the health and social services in order to help them meet their new responsibilities in terms of assessing and responding to community care needs. However, the guarantee that people already in (mainly private sector) places funded by the Social Security Agency have preserved rights to that funding *so long as they remain in that accommodation* created a new set of perverse incentives against needs-led care. Therefore, people whose needs for care change over time may be unable to move to alternative accommodation because the HSSBs are reluctant or unable to incur the costs of their care.

### Conclusion

The shift from long-stay hospital to community-based care is one of the most significant changes in policy affecting people with learning disabilities. It also has important organisational, staffing and resource implications for health and social services. The majority of former hospital residents in Northern Ireland continue to have only a limited choice of mainly 24 hour nursing home accommodation which, in turn, influences the configuration of services which they receive following discharge from hospital. Our study was descriptive in nature and it is impossible, therefore, – without any standards against which to compare the findings (other than comparisons with the English study) – to determine how *much* service should be received. Furthermore, Northern Ireland already has two-and-a-half to three times more nursing home places than England, Scotland or Wales. It is possible, therefore, that without alternative types of provision, the more dependent people currently still in hospital may not be discharged to appropriate accommodation; this, despite the DHSS commitment to “reduce to zero by 2002 the number of long-stay patients in hospital”. The opportunity to exercise choice over where to live is fundamental to the empowerment of service-users.<sup>3</sup> Therefore, the provision of a range of appropriate accommodation and service packages is important in ensuring that people do not experience transinstitutionalisation, but are given adequate opportunity and support to develop greater self-reliance and autonomy which, in turn, will allow them to better manage their behavioural problems and expand their social networks.

Although the findings of this study are based on a 1990-1992 data set, they are of considerable relevance to current policy and clinical practice because of the very slow pace at which community care for people with learning disabilities in Northern Ireland has developed when compared to elsewhere in the UK. For example, the largest of the three mental handicap hospitals currently provides care for 375 people compared to 459 in 1994 representing a reduction of only 18% over the last five years. Whilst significant organisational change has taken place since this research was carried out, it is important to note that less than 10 per cent of people with learning disability are ‘care managed’; the lion’s share (almost 80%) of care managed cases are older people.

Although it was not possible to determine to what extent service receipt was related to dependency, the type of community facility and, to some extent, the organisational factors currently involved in service delivery in Northern Ireland would appear to influence access to, and use of services. These findings reinforce the need for further research on the effectiveness and coordination of service delivery for former hospital residents with learning disabilities. Service planners and providers also need to be aware that the pattern of service provision, particularly in an evolving mixed economy of care, is likely to be very different for the more dependent cohorts of people who leave hospital in the future. However, improving or at least maintaining the quality of life and welfare of people with learning disabilities in Northern Ireland continues to be paramount in the policy of relocating care to the community.

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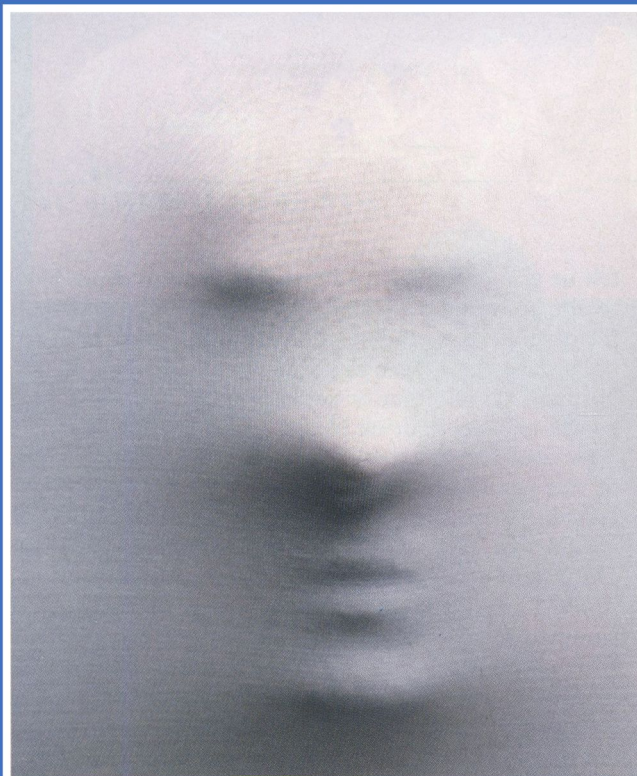
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# Depression

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