

PSYCHIATRIC FOLLOW-UP AND HEALTH SERVICES UTILISATION FOR PEOPLE WITH LEARNING DISABILITIES

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Introduction

Important policy changes over the last 30 years have greatly influenced the provision of services for people with learning disabilities. The closure of long-stay hospitals and the emphasis on community care have dominated the development of services. People with learning disabilities who either have mental illness and/or challenging behaviour (Emerson *et al.*, 1987) present particular problems for services (Murphy, 1994; Mansell, 1994a). Some different styles of re-providing services have emerged in response to the complex and diverse needs of this population (Bouras *et al.*, 1994; Day, 1993; Emerson *et al.*, 1989; Fletcher and Menolascino, 1989; Mansell, 1993).

There have been few studies evaluating the new services for people with learning disabilities and additional psychiatric disorder or challenging behaviour. Kearney and Smull (1992)

evaluated 150 people with learning disabilities, known to psychiatric services, who had been resettled in the community for five years, paying particular attention to day activities, medication, adaptive behaviour and factors associated with risk of re-hospitalisation. Data was finally collected on 62 men and 17 women with an average age of 51 years. Most of the people (42%) had mild, 25% moderate and 33% severe learning disabilities. Fifty eight percent had a dual diagnosis of learning disabilities and mental illness, whilst 27% had epilepsy. Most of the people (78%) were living in the original community placement at the 5 year follow-up but 10% were re-institutionalised. Mansell (1994b) offered a detailed account of repeated observations on activity levels of people with learning disabilities and severe challenging behaviour resettled in the community and associated staff performance over a period of 18 months. Bouras *et al.* (1993) described the medical

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and psychiatric needs of people with learning disabilities recently resettled in houses supported by staff.

It is important that services are evaluated to assess their efficiency and effectiveness. Information obtained from evaluation may not only reveal deficiencies but on a positive note, point the direction for future development. In the present age of cost consciousness, there is an increasing trend to use the data to balance quality and quantity. Services will also have to be assessed as to whether they meet needs.

It is now known that people with learning disabilities can live successfully in the community, using community services, including primary care and local hospital services. However, little is known of the long-term course and outcome of their mental health needs and their utilisation of services. This study aims to explore this by quantifying the utilisation of services and the frequency of psychiatric and behavioural problems of people with learning disabilities at 1 year and 5 years after their resettlement in a community house supported by staff. In addition, the satisfaction of the support staff with the psychiatric service was also assessed.

Method

In 1987, 74 clients were resettled in an inner London health district with a population of 320,000 from Darenth Park, a large institution for people with learning disabilities which was closed. The resettlement was planned and clients met their future carers and visited their future homes prior to their final move. They were resettled in ordinary

houses in the community converted to meet their needs. Two to five clients live in each house with the support of 10-15 direct care staff.

A community-based specialist psychiatric service supported the clients with learning disabilities and additional psychiatric or behavioural problems (Bouras *et al.*, 1994). This specialist service consisted of a consultant psychiatrist, trainee psychiatrists and community psychiatric nurses with dual training i.e. learning disabilities and mental health. This specialist service worked with community teams, but was not part of them. If admission was necessary, the client was admitted to a generic acute psychiatric ward in a district general hospital.

A clinical psychiatric assessment was made before resettlement by seeing the resident while still in Darenth Park, interviewing a care worker and looking at the case notes. Information was recorded in the "Assessment and Information Rating Profile", which is a semi-structured assessment procedure covering social and demographic characteristics, family information and history, medical history, level of learning disability, skills assessment, communication, community living skills, behavioural problems, clinical psychopathology rating scale, problem-oriented list and clinical management decision (Bouras and Drummond, 1992). The inter-rater reliability is ranging from 70% to 85% and the coefficient alpha from $r = 0.70$ to $r = 0.82$ for the clinical psychopathology rating scale; for the skills assessment scale it is the same. Clients were reassessed after one year and again after five years. The three sets of data are compared and presented.

Results

Study population

Of the 74 clients assessed before resettlement 54 were reassessed 5 years later. Of those who were not reassessed, 11 had died from natural causes before follow-up, 5 had moved out of the district, 3 could not be located and the carers of 1 client refused reassessment on ideological grounds.

These 54 clients consisted of 31 men and 23 women, with a mean age of 50 years (range 24-65 years). They had been institutionalised from 9 to 20 years. About half ($n = 25$, 46%) of the clients had severe, 24% ($n = 13$) moderate and 30% ($n = 16$) mild learning disabilities.

Behaviour problems

The frequency and severity of behaviour problems were recorded. The number of people with behaviour problems did not change significantly: 26 (48%) before resettlement, 25 (46%) at the one year and 23 (43%) at the five year follow-up.

The frequencies of most problem behaviours remained fairly stable. However, there was a significant increase in self-injury and inappropriate sexual behaviour. No difference was found for the total mean scores of frequencies and severity of behaviour problems before resettlement, at the 1 year and at the 5 year follow-up (see TABLE I).

Psychiatric Diagnosis

The frequency of psychiatric diagnosis remained constant. A psychiatric diagnosis based on DSM-III-R (American Psychiatric Association, 1987) diagnostic criteria was recorded for 9 (17%) clients before resettlement, for 11 (20%) clients after 1 year and for 10 (19%) clients after 5 years.

Utilisation of services

In an attempt to assess the impact of community care on the local services, clients and their carers were asked if they had used any of the services shown in TABLE II in the past year.

TABLE I
Frequencies of Behaviour Problems

	Before Resettlement (n)	1 year after Resettlement (n)	5 Years after Resettlement (n)
Aggression	10	10	14
Destruction of Property	10	10	14
Self Injury	8	5	12*
Absconding	10	6	6
Excessive Noise	18	13	16
Disturbance at Night	16	13	14
Stealing	7	4	7
Inappropriate Sexual Behaviour	4	5	9*

* $p < .05$

TABLE II
Utilisation of Services

	Within 1 Year of Resettlement (n)	After 5 Years of Resettlement (n)
GP	41	51
Psychiatry	26	17
Psychology	18	13
Other Therapists	7	26*
Medical Out Patient	8	21*
General Hospital Admission	6	7
Psychiatric Admission	3	3
* p<.05		

Within the first year of resettlement, 41 (76%) clients saw their GP, rising to 51 (94%) after 5 years. There was a significant increase in the attendance at hospital out-patient clinics after 5 years compared to 1 year. This reflects the high prevalence of serious medical conditions in this population. The other significant increase was in usage of other therapists i.e. occupational therapists, speech therapists and physiotherapists.

There was a slight, though statistically non-significant decrease in the number of clients seen by the specialist psychiatric service. This may reflect the changing to a more specific role of this service, concentrating on mental health problems and not just being a broad 'medical service'. Several General Practitioners initially thought that the role of the psychiatrist in the community was identical to their function in the institution as a medical officer.

Day Time Activities

All the clients had some form of day activity while they were in the institution, mainly attending the occupational therapy unit. However, only 64%

(n = 34) had an external day activity at the 1 year and 70% (n = 38) at the 5 year follow-up, highlighting current deficiencies in day-services. Day activities include attending local day centres for people with learning disabilities, drop-in centres, social clubs, local training colleges or any regular activity which occurs outside the house. In our study, the carers of 2 (4%) clients thought that they were too disabled to go out. Not one client was occupied for five days in the week and many only had one structured day activity in a week.

Social Life

All clients assessed shared their homes with other clients and 87% (n = 47) also met with other peers. Eighty per cent (n = 43) met with friends or relatives and of those who did not, 13% (n = 7) had no friends and 7% (n = 4) did not want to.

Accommodation

Most clients (n = 44, 83%) were happy with their accommodation at the

5 year follow-up. The reasons given by the 9 (17%) clients who were unhappy included 3 (6%) who did not get on with other clients, and 5 (9%) clients where the support staff felt the house was unsuitable e.g. the client needed a large garden to roam.

Role of Specialist Psychiatric Service

The accessibility to the specialist psychiatric service was rated as good or adequate by 41 (78%) of the support staff and only 6 (12%) found the service poorly accessible. In accordance with this, 7 (13%) thought that there should be more contact between the psychiatric service and the client while the rest were satisfied with the service. It is interesting that 9 (17%) admitted that they did not know the role of the psychiatric service.

Comments

The results of this study showed very little variation in behaviour problems and psychiatric diagnosis of people with learning disabilities prior to their resettlement in the community, at 1 and 5 years later. Consequently, misgivings about increase of mental health problems in people with learning disabilities resettled in the community were not justified. It is anticipated that these findings will remain constant for the foreseeable future, with the exception of the aging population developing dementia. The utilisation of the psychiatric service may then be considerably greater.

The deficiencies found in the provision of day care are most alarming. Community care without adequate and

appropriate day time activities is not acceptable. The study population had access to three adult training centres for people with learning disabilities, which were overwhelmed. Some of the more able clients attended local colleges, but many of those with severe learning disabilities were stuck at home. There is a danger that with the recent reforms introduced by the Community Care legislation (Caring for People 1989) with the consequence that several small organisations tend to become providers, responsibility for day care may be lost or become fragmented. Initiatives for vocational schemes and supported employment projects for people with learning disabilities living in the community are urgently needed.

The role of primary care for people with learning disabilities needs particular attention. Nearly all the clients in this study, visited their General Practitioner in the past year. However, the average number of people with learning disabilities registered with a GP is very low, perhaps not exceeding 5. Thus a GP does not have the opportunity to gain expertise from this client group. The GP finds the complex set-up of services available to people with learning disabilities rather puzzling and frequently refers to the specialist psychiatric service in an effort to gain access to more appropriate services. General practitioners require appropriate training opportunities, information on and close liaison with the specialist services available (Holt, 1992). A recognition of the extra time needed for them to carry out the task is also necessary. In turn, they will be able to provide clinical input, advice to the client and care staff on medical problems, arrange appropriate screening and

facilitate referrals to specialist services. The significant increase in usage of hospital medical services is most interesting and further work may be necessary to identify possible practical problems experienced by clients, staff and services.

This study provides further evidence that people with learning disabilities, even with long term previous hospitalisation and additional mental health needs, can be successfully maintained in the community 5 years after their resettlement, if they are supported by local service systems. Provision dedicated to the needs of people with learning disabilities should be available locally. Professional alliances, together with families and service users should expect to influence the shape and quality of future services and preserve the necessary resources.

Summary

Seventy four clients resettled from an institution for people with learning disabilities in an inner London district were assessed prior to discharge from there, after 1 year in the community and again after 5 years. The frequency of psychiatric diagnoses and behaviour problems remained fairly consistent over the 5 year period. The utilisation of local health service provisions was increased, particularly for medical out-patient attendance. The study highlights the lack of structured day activities. Overall, resettlement in the community for these people has been successful.

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