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# Professional staff and carers' views of an integrated mental health service for adults with learning disabilities

### AIMS AND METHOD

A study was undertaken to investigate the views of professional staff and paid and informal carers' views of a new integrated mental health service for people with learning disabilities.

### RESULTS

Twenty semi-structured interviews were conducted and transcribed.

Most staff and carers were generally satisfied with the in-patient facility. However, information exchange, ward rounds and the ward environment were identified as areas requiring improvement.

### CLINICAL IMPLICATIONS

Many of the participants had no previous experience of supporting a

person with learning disabilities and mental health problems in an in-patient setting. However, over time they became supportive of the mental health service and provided valuable input in improving the service provision for people with learning disabilities.

British government policy encourages the involvement of stakeholders in service initiatives (Department of Health, 2001). In addition, the role of the carers in supporting people with mental health problems has become the focus of further government guidance, through the National Health Service Reform and Health Care Professions Act 2002. A local study of carers in London showed that when visiting in-patient mental health units carers felt ignored, not given information and not included in after-care planning (Hervey & Ramsay, 2004).

In services for people with learning disabilities there has been little research on the experiences of healthcare staff and of paid and informal carers who support adults with learning disabilities and mental illness (Allen, 1999),

despite these individuals' greater reliance on social and professional networks compared with other service users. In our experience carers are often instrumental in enabling individuals to understand mental health legislation and treatment decisions. Carers also have a significant role within the psychiatric assessment process, as assessments of mental state of people with learning disabilities are often carer-led (Moss *et al*, 1993).

The authors have developed a new mental health service for adults with learning disabilities and mental illness (Hall *et al*, 2006). As part of this service we have four dedicated in-patient beds within a generic mental health service. Funding was approved at the outset for increased ward staffing levels, and learning disabilities mental health training is provided to nursing staff twice a



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year from within the local learning disabilities services. During the evaluation of this new service we interviewed professionals and paid and informal carers about their views.

## Method

A semi-structured interview was devised for the study which was used for both the service users (reported separately) and the professionals and carers. Originally we had planned to recruit only family carers. Surprisingly, the service users suggested we contact professionals in their service networks and in some instances refused to allow their own relatives or carers to be approached about the study.

## Interview process

The questionnaire included questions about all aspects of in-patient stay, such as reasons for admission, the ward environment, safety and security on the ward, the range of activities available, quality of nursing care, ward rounds, care programme approach meetings, quality of medical care and use of medication. The interviews were audiotaped and transcribed.

## Data analysis

Two of the authors (S.S. and C.P.) independently read the transcribed interviews to identify themes before each interview was analysed using specialist data management software (Qualrus version 1; <http://www.idea-works.com>). Open coding was used initially to link codes to segments of the original text. For external validity, another colleague with no other involvement in the study read excerpts from the interviews to ensure that they corresponded with the proposed themes.

The study received ethical approval from the local research ethics committee.

## Results

There were 20 participants: 12 professionals and 8 carers (4 relatives and 4 paid carers). Of the 20 participants, 11 were women (Table 1).

### Admission process

Risk to self and others was reported as the main reason for admission in 11 patients. The process of admission was felt to be satisfactory by all but three of the participants. Half felt that the admission had been of an appropriate length, whereas five felt it was too long and three that it had not been long enough. Twelve participants felt that the in-patient stay had a positive outcome in improving the mental state of and service input to the service user.

### Ward environment

Eight carers described the ward environment in negative terms, for example, 'stark and clinical', 'drab, gloomy and

**Table 1. Demographic profile and carer role of participants**

	<i>n</i>
Gender	
Male	9
Female	11
Carer role	
Family carer	2
Partner	2
Community team	
Care manager	4
Psychiatric nurse	2
Support worker	5
Psychologist	1
Other	
Residential manager/worker	3
Agency support worker	1

run-down' and 'depressing rather than welcoming'. Four of the participants said that they did not feel that the ward environment was adequate to promote mental well-being, contrasting it with other residential environments for people with learning disabilities. However, a third of participants commented positively on the availability of single rooms and space on the ward.

All participants thought that the ward was a relatively safe environment for the service user. A few concerns related to the safety of personal possessions, as service users had reported items missing during the admission. Four participants suggested that a 'signing book' could improve security on the ward. Two paid carers were quite negative about the main door to the ward and the door to the female dormitory being locked:

'I suppose being an acute psychiatric unit you can't make it really homely because you've got to ensure it's a safe environment.'

### Activities and socialisation

Half of the respondents thought that there was a good range of activities available on the ward, such as relaxation, art, crafts and music, as well as talking to staff and friends on the ward, watching television and playing games. Seven participants felt that additional support around daily living and further psychological interventions should also have been offered. Participants reported that most service users were able to make friends with other service users who did not have learning disabilities.

### Nursing and medical care

Nursing staff were described as 'nice', and 'professional', although some paid carers felt that they had not had enough contact with the staff during the admission. No one reported significant concerns with nursing care. The monitoring of and investigations into patients' health were thought to be exceptionally good by three participants; although a similar number described this as lacking. Communication with nursing staff and doctors



and use of agency nurses were described as creating occasional problems in caring for the service users or as hindering adequate contribution to care plans.

## Use of medication

All participants were satisfied with how decisions regarding any changes in medication were explained and thought that the medication given was appropriate. However, three felt that they needed more information about its indications and side-effects.

## Ward rounds

With the exception of one part-time professional, all carers and professionals had attended at least one of the regular weekly ward rounds or a pre-discharge care programme approach meeting. Nine participants described how it was useful to meet regularly with ward staff and other professionals, and felt it provided a regular opportunity to receive updates on progress and was a useful forum for discussion:

'I think it's good that the patient becomes involved and is invited into that ward round and also anyone else that's involved in the life of that person whether it be a carer, next of kin, you know, whoever.'

The majority of those interviewed were able to participate in discussions within the ward rounds; however, six were concerned about the number of people attending each time, and they and the service user had felt overwhelmed by this. Seven interviewees also felt that the ward round, which is chaired by the consultant, did not always allow for effective participation of carers and service users.

## Discussion

We obtained the views of professionals and carers involved in caring for adults with long-term mental illness and mild learning disabilities who had been using a new, integrated in-patient psychiatric service. We have not found any similar studies for those with learning disabilities, although there are several studies of adults with mental illness but without learning disability (Gralton et al, 2001; Lacey & Thomas, 2001). Most of the participants had little experience of engagement with in-patient psychiatric services; those who did were formal carers, such as support workers or care managers.

Comments about the physical environment mirror the findings of a number of studies of in-patient psychiatric care (Sainsbury Centre for Mental Health, 1998; Rose, 2001) that have found in-patient units unsatisfactory and poorly maintained. Our participants, particularly those with little experience of psychiatric in-patient care, highlighted the need for alternatives to admission for adults with learning disabilities, the importance of a clean and stimulating ward environment, the essential issue of proactive communication between the in-patient and community teams, and the facilitation of access to

advocacy. One of the consequences of the extensive service networks of the adults with learning disabilities was that ward rounds sometimes became very crowded and quite intimidating for service users and carers alike.

## Service culture

Great effort had been made during the service development stage to address shortcomings of previous arrangements. There was wide consultation with local stakeholders, ongoing training of psychiatric nursing staff to increase awareness of issues relevant to caring for people with learning disabilities, and continuous input by community team members to in-patients, which included specialist sessions for psychology, speech and language therapy, occupational therapy and community nursing, as well as support with activities.

The participants in this study were positive and encouraging about the new service but recognised that there are several areas where further progress could be made. We have tried to address the issues raised by implementing the following changes: we have been asking service users to indicate who they would like to be present when seen in the ward round and we have offered to meet with them and key staff outside the ward round. We have started to produce accessible information leaflets about the in-patient process as part of the respective service plans. We continue to provide ongoing seminars on aspects of mental health, including the care programme approach, at least annually to both service professionals and formal carers as part of the service training programmes.

We acknowledge that it is essential to work together with carers of adults with learning disabilities and mental health problems. We have made some progress in improving our current service compared with past provision. Future work should explore in depth the attitudes of different stakeholders towards mental health services for adults with learning disabilities, including nursing staff and managers of the in-patient adult mental health services. The publication of a guide for the improvement of mental health services for adults with learning disabilities, *Green Light for Mental Health* (Department of Health, 2004), is a significant recent development which also may help to improve local mental healthcare pathways and support to people with learning disabilities.

## Declaration of interest

None.

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## Clozapine and speech dysfluency: two case reports

### AIMS AND METHOD

We describe two patients, both diagnosed with psychotic illnesses, who developed stuttering while being treated with clozapine.

### RESULTS

In both patients the stuttering was severe and significantly impaired

progress towards recovery. Deviant speech dimensions and voice quality were consistent with dysarthria and dystonia.

### CLINICAL IMPLICATIONS

Patients who develop abnormal electroencephalogram activity and those who have a family or personal

history of stuttering might be at increased risk of developing speech problems with clozapine. Speech dysfluency might be a consequence of clozapine's action in lowering the seizure threshold. Potential management strategies include the use of sodium valproate and changing the type of antipsychotic.

Stuttering is defined as a disturbance in the normal fluency and time patterning of speech, characterised by sound and syllable repetitions, sound prolongations and broken words (American Psychiatric Association, 1994). The prevalence of stuttering in the general population is slightly less than 1%, with a peak age at onset in early childhood (Craig et al, 2002). Causation remains uncertain, but many have argued that people who stutter have a subtle neurological dysfunction that disrupts the precise timing required to produce speech (Guitar, 1985). A family history of stuttering is evident in about 60% of people with an onset in childhood (Andrews et al, 1988).

A link between schizophrenia and stuttering is recognised and Rogers (1985) reported a 2% prevalence rate in patients with chronic schizophrenia. The relationship between stuttering and antipsychotic treatment is complex. There are a number of case reports of patients who have developed stuttering when prescribed phenothiazines (Nurnberg & Greenwald, 1981; Adler et al, 1987). Conversely, trifluoperazine and haloperidol have been shown to be effective treatments for the stuttering associated with schizophrenia (Menkes & Ungarvi, 1993).

There are no previous reports in the British medical literature of a link between clozapine and stuttering. However, four cases have been reported in North America. Two reports describe stuttering in young

women prescribed clozapine, one at a dose of 125 mg, the other at 400 mg (Thomas et al, 1994; Ebeling et al, 1997). In two other patients the development of stuttering has been associated with seizure activity. Supprian et al (1994) described a 49-year-old woman who began to stutter when prescribed 700 mg clozapine. On 750 mg clozapine she suffered a generalised epileptic seizure accompanied by polyspike wave activity on an electroencephalogram (EEG). She was treated with sodium valproate; the stuttering remitted and did not recur when she was prescribed 600 mg clozapine daily. Duggal et al (2002) reported a 28-year-old man who developed stuttering on 300 mg clozapine daily. At 450 mg clozapine he suffered a generalised seizure. As the dose was reduced to 200 mg the stuttering stopped. Sodium valproate was later started.

In this paper, we describe two patients who developed stuttering while being treated with clozapine on the same ward in a high secure hospital.

## Case reports

### Patient 1

A 62-year-old man, a former market trader, was detained in hospital following an assault on his partner. He has no