

## FEATURE ARTICLE

# Practice standards to improve the quality of family and carer participation in adult mental health care: An overview and evaluation

**Richard Lakeman**

*School of Nursing, Dublin City University, Glasnevin, Dublin, Ireland*

**ABSTRACT:** *Mental health services are required to involve family, carers, and service users in the delivery and development of mental health services but how this can be done in routine practice is challenging. One potential solution is to prescribe practice standards or clear expectation relating to family involvement. This paper describes practice standards introduced to an adult mental health service and a study that aimed to evaluate the impact of the standards on practice. Hospital and community files were audited before and after the introduction of standards for evidence of participation and surveys of carers and consumers relating to the quality of participation were undertaken. Increases in documented carer participation were found, particularly in relation to treatment or care planning. The expressed needs relating to participation varied in hospital and community settings. The majority of carers and service users were satisfied with their level of participation. The introduction of practice standards is an acceptable, inexpensive, and feasible way of improving the quality of family and carer participation, but gains may be modest.*

**KEY WORDS:** *carer participation, consumer participation, family involvement, mental health.*

## INTRODUCTION

Families and carers ought to be regarded as allies, partners, and collaborators with consumers and health professionals in the treatment and rehabilitation of people diagnosed with mental illness (Commonwealth of Australia 1996). However, surveys in Queensland (Hodgson *et al.* 2002), across Australia (Mental Health Council of Australia & Carers Association of Australia 2000), and internationally (Biegel *et al.* 1995; Jakobsen & Severinson 2006) suggest that many families and caregivers of

those diagnosed with mental illness feel excluded by health professionals from processes of assessment, treatment planning, and care. Engaging families and other caregivers in mental health services in meaningful ways is a major challenge for health services (Sherman *et al.* 2005). In Townsville, one response to improving the quality of family participation in mental health services was the introduction of practice standards relating to the identification and involvement of carers in adult mental health care. This paper presents an overview of this project and its evaluation.

**Correspondence:** Richard Lakeman, School of Nursing, Dublin City University, Glasnevin, Dublin 9, Ireland. Email: richard.lakeman@dcu.ie

Richard Lakeman, DipNsg, BN, BA Hons, PGDip(psychotherapy), Doctoral Candidate.

This research was undertaken at Queensland Health in Townsville, Queensland, Australia and was approved and monitored by the Townsville Health Service Human Research Ethics Committee. The protocol conformed to the provisions of the Declaration of Helsinki. All participants gave informed consent and patient anonymity has been preserved.

Accepted August 2007.

## BACKGROUND

Family and non-professional carers provide the bulk of care and support to those who enter and use mental health care systems. Their first contact with psychiatric services is frequent during a period of crisis, and after the accumulation of much doubt, guilt, and exhaustive efforts to make sense of their loved ones' behaviour. These

first and sometimes subsequent experiences of negotiating the system are almost always bewildering and people struggle to have their concerns heard (Karp 2001). Mental health professionals need to engage with and listen to family members and carers because they know the person intimately, are key informants in making sense of symptoms, and are the natural source of support to the individual. Carers also have their own mental health and support needs which if not addressed can undermine the capacity of people to care for each other.

For the purposes of this paper, a family is two or more people who regard themselves as a family and who perform some of the functions that families typically perform. A carer is a person who provides significant unpaid care and support to a person with a mental health issue and may or may not be regarded as family. Notions of family and carer differ (Cleary *et al.* 2006) and may involve different bonds, duties, and responsibilities. However, in the interests of parsimony these terms will be used interchangeably.

It is now accepted that the medical treatment of mental illness is greatly enhanced with combinations of family interventions (Bustillo *et al.* 2001) and that these approaches are cost-effective (Mithalopoulos *et al.* 2004). Models of community mental health care are enhanced through family collaboration (McFarlane 1997; McFarlane *et al.* 2000). In Western Australia, South Australia, and the Northern Territory, the rights of carers are enshrined in 'Carers Recognition' legislation (The Carers Recognition Act 2005, 2004, and 2006, respectively). These Acts require that the role of carers is recognized by including carers in the assessment, planning, delivery, and review of services that impact on them. The views and needs of carers must be taken into account when health and welfare decisions are made that impact on their role. The Australian National Standards for Mental Health Services (Commonwealth of Australia 1996) mandate the participation of consumers and carers in the development and evaluation of mental health services, and as partners in the process of care planning and evaluation. Despite this, and convincing evidence of the benefits of family participation, less than 50% of respondents in a survey of carer participation in Queensland stated that mental health professionals 'always' or often discussed treatment plans with carers, or involved them in discussions (Hodgson *et al.* 2002).

### The Townsville context

Townsville District Mental Health Service might be considered fairly representative of a regional mental health service in Australia. Consistent with the literature, anecdotal

reports suggested that many carers felt excluded from care. At the time this research was undertaken, Townsville had an urban population of approximately 155 000 people and provided acute inpatient services to a number of outlying towns. The adult mental health services consisted of an acute mental health inpatient unit (30 beds), outpatient and psychotherapy clinics, a community case management team, a mobile intensive treatment team, a small day centre, a consultation and liaison team to the general hospital, and a crisis/intake team. Some services such as an early intervention in psychosis programme and family/carer support programme were provided in partnership with non-governmental organizations. As the major tertiary mental health centre in North Queensland, Townsville was the base for a zonal inpatient rehabilitation facility, secure inpatient services, and provided outreach services of various kinds to remote communities in the region. The Townsville services have since undergone considerable change.

### Development of practice standards

In Townsville, concern about the amount and quality of carer involvement, particularly as it related to acute inpatient settings, led to the formation of a steering group representing a wide range of community groups and interests (see Acknowledgements). The group examined the Australian National Standards for Mental Health Services (Commonwealth of Australia 1996) and limited literature on carer participation at the time and concluded that there were no published guidelines which made explicit in detail what general adult mental health ought to do to improve family participation. The group developed a set of expectations or standards of practice as they related to carer participation in the adult branch of the service (outlined in Table 1). According to Cleary *et al.* (2006), formal frameworks are necessary to promote the contribution of carers. Considerable local consultation occurred with a wide range of interested groups to arrive at some reasonable but not procedurally burdensome guidelines that reflected the choice of the service user and balanced the rights, responsibilities, and interests of consumers, carers, and mental health practitioners. These outlined time frames for sharing information and involvement of carers in aspects of mental health care in the hospital and community settings.

The practice standards were predicated on service user choice and mandated mental health practitioners asking the person who they would like to be involved in their care and the extent and nature of involvement. Guidelines were developed which addressed anticipated service user

**TABLE 1:** *Practice standards relating to family/carer participation**Family/carer rights and responsibilities in sharing and exchanging information*

- To give information to assist the clinician and aid diagnosis, assessment, and understanding of the role of the family/carer in the consumer's life
- To receive information from the treating team about diagnosis and strengths of the consumer
- To receive information about strategies that would help the consumer and strategies that would help the carers
- To participate in the development of the Individual Service Plan and where appropriate, be a signatory and/or be involved in the delivery
- To participate in a regular feedback process about the progress of the consumer and the Individual Service Plan

The level of information shared may vary from time to time according to individual situations and will be subject to regular review.

*Principles*

- Family/carer and consumer participation depends on being an open process. Respect, discretion, and confidentiality are maintained within consumer/carer/family/clinician relationships. This applies to all consumers, voluntary or involuntary.
- Everybody has the right to support and advocacy. Involuntary consumers can nominate an allied person (who may or may not be their family/carer member) under the Mental Health Act 2000. There is a separate procedure for this. Voluntary consumers are encouraged to identify someone who can fulfil a similar role for them.
- Consumers and family/carers reserve the right not to participate and reserve the right for some information not to be shared.
- Family/carers have the right to referral to appropriate organizations to receive information, education, and support around issues of caring.

*Quality assurance standards of the mental health service*

## For inpatient admission

1. Family/carer involvement in information sharing and exchange of information at point of entry, or as soon as practically possible, but within 3 days
2. Families/carers to receive information about diagnosis, strengths, and management strategies within 5 days
3. Discharge planning process and participation in Individual Service Plan to begin within 1 week
4. Feedback and review weekly while an inpatient, unless otherwise arranged

## Community treatment

1. Family/carer involvement in information sharing and exchange of information (at point of entry) or by the end of the second interview or within 2 weeks of beginning case management
2. Family/carer to receive information about diagnosis, strengths, and management strategies within 1 month
3. Discharge planning process and participation in Individual Service Plan to begin within 1 month
4. Feedback and review 3 monthly unless otherwise agreed

refusal of carer involvement (see Fig. 1) which ensured that carers should at a minimum receive general information about mental illness and agencies that might support them. Additional guidelines were also formulated for the rare circumstances in which health professionals might suspect or know that disclosure to nominated people may not be in the best interest of the service user, for example, in cases of domestic violence or child custody disputes. In all cases, decisions, judgements, and actions relating to carer participation were to be documented.

### Promotion of the practice standards

Two part-time project officers, one a mental health nurse and one a person with experience of the service as a carer, were employed to promote the standards and to evaluate their impact. The practice standards were adopted as policy after a formal and well-publicized launch in October 2004. Promotion included the printing and wide distribution of brochures outlining the standards, posters in communal and staff work areas and an email to all staff in the district with attached copies of the standards (see [http://www.health.qld.gov.au/townsville/imhs/consumer\\_](http://www.health.qld.gov.au/townsville/imhs/consumer_)

[info.asp](http://www.health.qld.gov.au/townsville/imhs/consumer_info.asp)). Briefing sessions were held for health staff, non-governmental organizations, and the public. These included a series of video clips narrated by family members that illustrated positive outcomes associated with improved relationships with carers. Attempts were made to contact all users of community mental health services and a project officer regularly attended patient/staff community meetings on the acute inpatient unit which served to raise people's awareness of the standards. Additionally, a regular newsletter relating to family participation was posted to all staff.

### Study purpose

The principle objective of the evaluation was to determine whether or not the introduction of the practice standards made a difference to the level and quality of carer participation. A secondary purpose was to provide a rich description of the experience of family and carer participation. This report focuses on the evaluative component of the study and the perceptions of the researcher regarding the file audit. Qualitative data are reported elsewhere (Lakeman 2008).

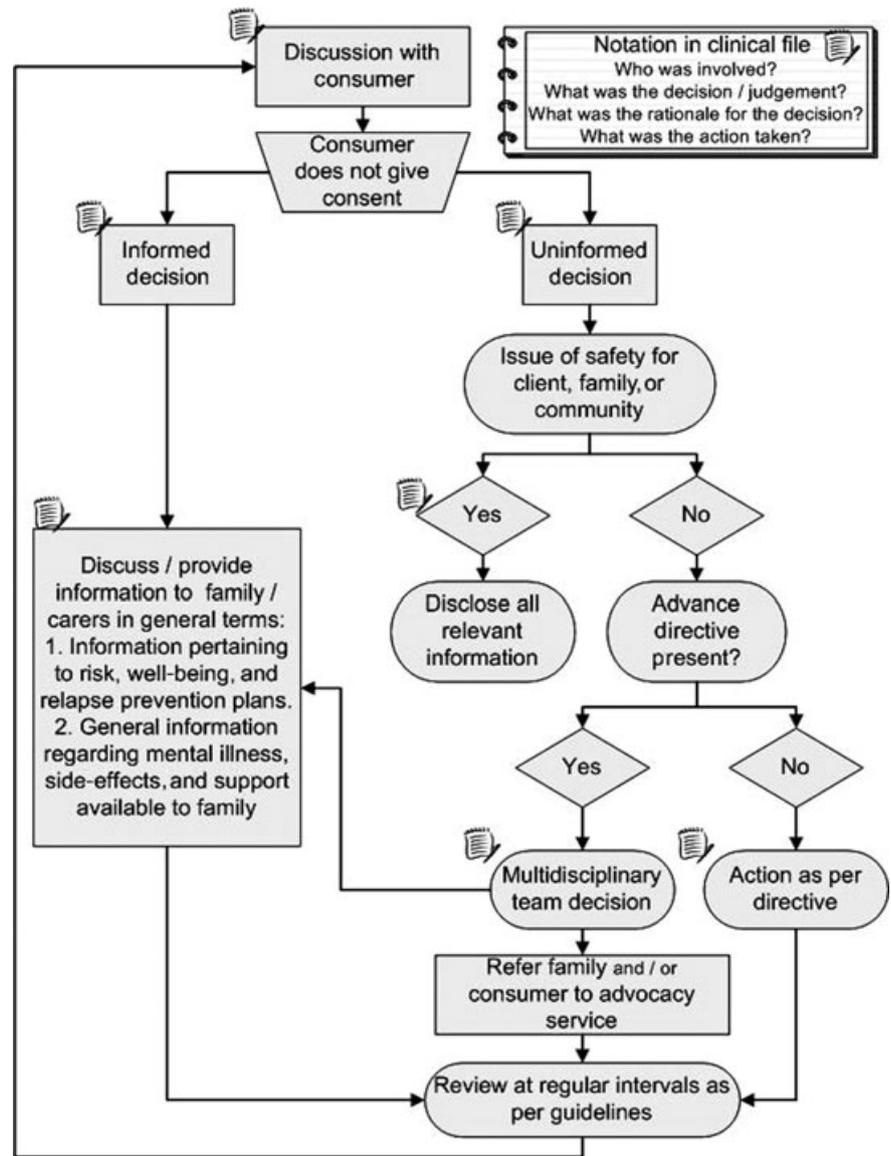


FIG. 1: When the consumer does not consent to information sharing.

**METHODS**

Chart audits of inpatient and community files were undertaken for periods before and after introduction of the practice standards. These mainly addressed the extent of carer participation. ‘After only’ surveys were also completed by service users and carers that addressed the quality of participation from their perspectives. The research was approved and monitored by the Townsville Health Services Human Research Ethics Committee.

**File audit**

Thirty files were randomly selected from those admitted to the inpatient unit and 25 from those who were active

clients of the case management service 3 months before the introduction of the standards. A further 30 inpatient and 29 community files were reviewed 6 months after the introduction. The notes relating to all inpatient episodes within the preceding 3 months, or 3 months of care in the community, were reviewed.

Only ‘general case management’ files were examined. General case management services provided medium intensity clinical support to people in community settings by individual nurses, social workers, psychologists, or occupational therapists assigned as ‘case managers’. The number of clients to case manager was 17 (range 7–33, SD = 8) at the post-introduction audit point. All such clients saw a registrar or consultant psychiatrist at least

every 3 months and many were connected with other non-governmental organizations or support agencies.

At the time separate inpatient and community files were maintained and all disciplines used the same assessment documents and progress notes. All notes in these files relating to the preceding 3 months were audited using a template which included basic demographic, diagnostic and Health of the Nations Outcome Scale (HoNOS) scores. These demographic data were useful to provide a profile of participants and determine how representative people were of service users in hospital and community care settings. The presence or absence of a formal service plan and any documented contact by a health professional with a family member was noted including who initiated the contact, the stated reason for contact, and the mode of contact. Any documented exceptions to family/carer involvement were noted (e.g. patient or family refusal) and notes were compiled to illustrate examples of documented practice. Some of these are discussed under 'Observations on the audit'.

### Family and carer participation surveys

A questionnaire was developed by the reference group and taken back to members of their organizations for trial and comment before inclusion. It consisted of the eight statements that were rated on a Likert scale from 1 to 10 where 'Strongly disagree' was coded 1 or 2, 'Disagree' 3–5, 'Agree' 6–8, and 'Strongly Agree' 9 or 10. On the questionnaire these were represented on a line. A 10-point scale was thought to offer greater discrimination and sensitivity to different perceptions. The questionnaire addressed some aspects of the practice standards directly, for example, 'Mental health workers consulted family/carers as they planned services and medication', and others addressed issues such as satisfaction with involvement, or information shared. The questions were changed marginally for carers and consumers and were as follows:

- Mental health workers consulted my family/carers [me] as they planned services and medication
- Mental health workers were interested in what my family/carers [I] could tell them
- Mental health workers gave detailed information about illness to family/carers [me]
- Family/carer involvement enhanced care and treatment
- Family/carers [I was] were provided with useful information about where they [I] could obtain help and support

- I was satisfied with the level of involvement of family/carers during this admission/period
- Family/carers [I/we] initiated contact with mental health services
- Family/carers [I] had their [my] questions answered satisfactorily by mental health workers

Three open-ended questions relating to perceived obstacles to carer involvement, how involvement had helped (or otherwise), and how it could have been improved. These questions yielded a considerable amount of qualitative data (see Lakeman 2008).

Three months after the introduction of the practice standards, attempts were made to contact all people newly admitted to the acute inpatient unit prospectively over a 5-month period and all people receiving general case management services (except where the treating doctor or case manager advised against contact). Inpatients were contacted in-person and case management clients by phone, or letter. They were invited to complete the survey at their own leisure or with the assistance of a researcher. Those who participated were asked to nominate someone who had been involved in their care to also contribute. Both carers and consumers were asked to consider either the most recent inpatient admission or the previous 3 months of care in answering questions about carer participation.

### Data analysis

Survey responses and audit responses were initially gathered in paper format, transposed onto excel spreadsheets and imported into the statistical analysis package SPSS which was used to generate descriptive and inferential statistics. Differences in means were examined using *t*-tests for interval data after testing for skewness and transformation using log10 if necessary. Pearson's R was most commonly used to examine relationships between variables. The two chart audit points are referred to as pre-introduction or post-introduction (of practice standards).

## RESULTS

### Inpatient chart audits

The main results of the chart audits for the acute inpatient unit are outlined in Table 2. There were no significant differences between the characteristics of the service user group pre or post introduction of the standards; that is, age, living circumstances, Mental Health Act status, diagnostic profile, and number of repeat admissions were similar. In the post-introduction group, more people had

**TABLE 2:** Summary of inpatient file audit results

Inpatient file audit	Pre-introduction of practice standards	Post-introduction of practice standards
Number of files reviewed	30	30
Admission episodes reviewed	46 (20% of 235 episodes)	48 (21% of 228 episodes)
Admissions per person	M = 1.5, SD = 1, Range 1–4	M = 1.6, SD = 1, Range 1–5
Age	M = 36.5, SD = 12.66, Range 16–72	M = 36, SD = 12.58, Range 17–66
Gender	17 (57%) males	13 (40%) males
Under Mental Health Act	16 (53%)	15 (50%)
Most common ICD-10 diagnosis	Bipolar affective disorder (43%) Schizophrenia/schizotypal (40%) Depressive disorder (10%)	Schizophrenia/schizotypal (37%) Bipolar affective disorder (30%) Neurotic/stress related (17%)
Housing type		
Living with family	11 (37%)	16 (53%)
Homeless	7 (23%)	5 (17%)
Cumulative HoNOS scores	M = 9.7, SD = 5.2, Range 1–20	M = 12.9, SD = 6.4, Range 2–31
Mean item HoNOS score	M = 0.75, SD = 0.46	M = 1.07, SD = 0.53
Next of kin notified of admission	17 (57%)	22 (73%)
Documented exceptions to family involvement	17 (57%)	9 (30%)
Due to patient refusal	5	5
Due to family refusal	2	1
Due to estrangement or other	10	3
Family/carer contacts		
Files with documented contact	18 (60%)	22 (73%)
Number of documented contacts	58 (M = 3.2 per file)	137 (M = 6.2 per file)
Documented contact with		
Parent	36 (62%)†	61 (44%)
Sibling	1 (2%)	30 (22%)
Spouse	11 (19%)	22 (16%)
Other	10 (17%)	24 (18%)
Main reasons for contact		
Treatment plan formulation/review	1	24
Discharge planning	15	27
Information exchange	24	22
Formal assessment interview	7	16
Documented contact with		
Doctor	19	55
Nurse	46	65
Other	3	8

†Percentage of actual contacts. HoNOS, Health of the Nations Outcome Scale; SD, standard deviation.

HoNOS completed around the time of admission rather than nearer to discharge and had higher mean item scores ( $t = -2.456$ ,  $d.f. = 58$ ,  $P < 0.05$ ). Problems with hallucinations and delusions followed by other mental and behavioural problems had the highest mean scores in the post-introduction group, and problems with depressed mood followed by overactive, aggressive, or disruptive behaviour were the highest in the pre-introduction group. There was no significant difference in HoNOS scores between those who lived with family and those who did not.

In the pre-introduction group 37% of people lived with family, compared with 53% of the post-introduction group. Those that were identified as living with family or carers had higher mean number of documented contacts

between health professionals and family ( $t = 2.14$ ,  $d.f. = 42$ ,  $P < 0.05$ ). Sixty-seven per cent of pre-introduction files and 87% of post-introduction files had discrete service/care plans. A more modest (14%) increase in the number of files that contained service plans that made reference to family or carer participation was found. With few exceptions plans had a family member or carer listed and the relationship was described, for example, parent or sibling. The pre-introduction audit revealed seven files (23%) and the post-introduction audit revealed 11 (37%) files in which expectations regarding communication with families or carers were documented, for example, a plan outlining circumstances under which nominated carers should be contacted.

In 36% of pre-introduction files and 23% of post-introduction files, there were clear and often extreme examples of discord in significant relationships leading up to the admission. Divorce proceedings, alleged infidelity of a spouse, domestic violence, and child custody disputes often appeared to be antecedents to admission. In several cases, the patient alleged that a parent had sexually abused them.

Overall, there was an increase in the number of files in which contact with family was documented ( $n = 18$  vs  $n = 22$ ) and an increase in the number of contacts in each file ( $n = 58$ , mean = 1.9 vs  $n = 137$ , mean = 4.6) from the first to the second audit. These differences approached significance ( $t = 1.865$ , d.f. = 58,  $P = 0.07$ ). There was an increase in the number of examples of family being involved in treatment planning with only one example of this occurring in the pre-introduction audit and 24 examples in nine files in the post-introduction audit ( $t = 2.788$ , d.f. = 58,  $P < 0.05$ ). Treatment planning often involved making decisions about the patient's immediate

care and treatment on the ward. This mostly occurred in the context of a formal meeting involving the patient, family, and one or more health professionals. Nurses, followed by doctors had by far the greatest documented contact with carers. There was a significant (189%) increase in the documented carer contact with doctors ( $t = 2.44$ , d.f. = 58,  $P < 0.05$ ) and a 41% (ns) increase with nurses.

### Community case management chart audits

Overall, 249 files were identified as open to case management services at the pre-introduction audit and 231 files post introduction of practice standards. Twenty-five and 29 files were reviewed, respectively. All files reviewed had been open for longer than 3 months. The main results of the file audit are outlined in Table 3. Patients in the post-introduction group were somewhat younger, predominantly male, less culturally diverse, and a higher percentage were being treated under the Mental Health Act

**TABLE 3:** Summary of community file audit results

Community file audit	Pre-introduction of practice standards	Post-introduction of practice standards
Number of files reviewed	25 (10% of 249 open files)	29 (13% of 231 open files)
Age	M = 42.4, SD = 13, Range 22–72	M = 34.4, SD = 10.3, Range 20–61
Gender	15 (50%) males	22 (76%) males
Under Mental Health Act	5 (20%)	9 (31%)
Most common ICD-10 diagnosis	Schizophrenia (52%) Bipolar affective disorder (24%) Organic disorder (8%)	Schizophrenia (55%) Bipolar affective (10%) Organic disorder (10%)
Housing type		
Living with family	12 (48%)	17 (59%)
Living alone	4 (16%)	6 (21%)
Cumulative HoNOS scores	M = 10.3, SD = 7, Range 3–26	M = 7, SD = 6.1, Range 0–26
Mean item HoNOS scores	M = 0.86, SD = 0.59	M = 0.59, SD = 0.51
Documented exceptions to family involvement	8 (32%)	9 (31%)
Due to patient refusal	1	4
Due to family refusal	2	2
Due to estrangement or other	5	3
Family/carer contacts		
Files with documented contact	9 (36%)	12 (41%)
Number of documented contacts	27 (M = 3 per file)	33 (M = 2.8 per file)
Documented contact with		
Parent	12 (40%)†	19 (35%)
Sibling	6 (22%)	2 (4%)
Spouse	2 (7%)	4 (7%)
Son/daughter	4 (15%)	21 (39%)
Other	3 (7%)	8 (15%)
Main reasons for contact		
Treatment plan formulation/review	2	6
Discharge planning	1	1
Information exchange	12	17
Formal assessment interview	1	6

†Percentage of actual contacts. HoNOS, Health of the Nations Outcome Scale; SD, standard deviation.

(31% vs 20%). Most people in both groups were diagnosed with schizophrenia or a related disorder.

Only 52% of patients in the pre-introduction audit had HoNOS completed, whereas 93% had HoNOS completed post introduction. Problems with occupation and activities followed by problems with relationships and other mental and behavioural problems had the highest means in the pre-introduction group, whereas other mental and behavioural problems followed by problems with depressed mood had the highest means in the post-introduction group. Differences were not significant.

Sixteen per cent of pre-introduction files and 55% of post-introduction files outlined expectations regarding communication with families or carers. Thirty-two per cent of both groups had some documented exception to family/carer involvement. The most frequently cited reason for non-involvement was 'estrangement' because of distance, that is, family lived in another state or city and had little contact with the person. Patients also refused involvement for a range of reasons. For example, one person did not wish for family to be involved in treatment lest they discover that he smoked cannabis. Another's spouse was seriously ill and the person assumed a caregiver role and did not wish to further burden their spouse. Several people were clear about their desire for independence, for example, 'I look after myself and that's the way I like it'; another acknowledged that they had supportive parents but at the time stated 'I believe I can cope with work and live my own life'.

There was a modest increase in the number of files with any family contact (36% vs 41%) and no change in the mean number of documented contacts. The majority of contacts (52.4% vs 63.6%) were initiated by health professionals, with only six documented examples of family or carers initiating contact in each group. Only two contacts at pre-introduction and six at post-introduction audit related to formal treatment planning/review. One note stated that the patient requested that a family member be involved in discharge planning whilst an inpatient (although there was no record of a meeting taking place). One person accompanied their relative to an assessment interview with a doctor. Three people rang the case manager directly to express concerns about their family member's mental status.

### Inpatient consumer and carer survey

A total of 41 consumers completed the survey relating to family/carer participation during an admission episode

and 88% ( $n = 36$ ) provided permission to contact a carer. Of these, 27 carers could be contacted and all agreed to contribute. The average age of consumers who participated in the hospital group was 35.8 years (range 19–65,  $SD = 13.09$ ). Thirty-seven per cent ( $n = 15$ ) were under some form of compulsory treatments under the Mental Health Act at sometime of their hospital stay. Forty-nine per cent ( $n = 20$ ) were female. Consumers who elected to participate in the research had periods of hospitalization ranging from 3 to 120 days (mean = 27.41,  $SD = 11.55$ ). Sixty-eight per cent ( $n = 28$ ) had lengths of stay less than 3 weeks. The 13 people who had stays over 3 weeks accounted for 742 days of hospitalization or 71% of the total bed days for the group.

Parents were most frequently nominated as the carer to be contacted by consumers (mothers 51.9%, fathers 14.8%, spouse 11.1%, sibling 11.1%). Table 3 summarizes the responses to the survey questions. The majority of consumers (78%) and carers (70%) were satisfied with the level of carer participation in inpatient care. This was despite only 52% of family/carer respondents agreeing that they had been consulted about care and treatment. Fifty-six per cent of consumers reported that their family/carers had their questions satisfactorily answered, but 78% of family/carers agreed with this statement. The highest mean scores were in response to the question that family and carer involvement enhanced care and treatment.

For most questions in both groups, approximately 10% of respondents strongly disagreed with the statements. However, on only one question answered by family/carers, 'I was provided with useful information about where I could obtain help and support', did those that answered 'strongly disagree' (19%) outweigh those that answered 'strongly agree' (15%). There were no significant differences between consumer responses or family/carer responses to any of the questions, but neither were there significant correlations between groups. All items completed by consumers were strongly positively correlated ( $r = 0.54$ – $0.8$ ,  $P < 0.05$ ). Carer responses were more heterogenous with much weaker relationships between items. The items 'Our involvement enhanced care . . .' and 'we initiated contact with mental health services' had particularly weak relationships with other items. Satisfaction with level of involvement in care was strongly correlated with perceptions of being consulted ( $r = 0.68$ ,  $P = 0.01$ ), perceptions that mental health workers were interested in what they had to say ( $r = 0.72$ ,  $P < 0.01$ ), receiving detailed information about illness ( $r = 0.54$ ,  $P < 0.5$ ), and questions being answered satisfactorily ( $r = 0.50$ ,  $P < 0.01$ ).

### Community consumer and carer survey

A total of 86 'case management' consumers completed the survey relating to family/carer participation over a 3-month period. This was a response rate of 41% from a potential pool of 210 (which allows for those whose letters were returned unopened). Fifty-seven per cent ( $n = 49$ ) of consumers provided permission to contact a family member or carer. Of these 33 people were able to be contacted and agreed to contribute (67% response rate). The average age of consumers who participated was 42.3 years (range 20–78,  $SD = 12.2$ ). Fifty-nine per cent ( $n = 51$ ) were male. Sixty-four per cent of participants had a diagnosis from the ICD-10 schizophrenia spectrum of disorders. This was followed by bipolar affective disorder (13%).

Parents were most frequently nominated as the carer to be contacted and mothers accounted for 66.7% of all respondents. Those consumers who nominated a family/carer for contact were significantly more positive in response to all statements except satisfaction with family involvement. When carers were paired with consumers, carers rated the statements that their involvement enhanced care ( $t = 1.995$ ,  $d.f. = 31$ ,  $P < 0.05$ ) and that health professionals were interested in what they had to say ( $t = 2.398$ ,  $d.f. = 32$ ,  $P < 0.05$ ) more highly than consumers. All items were significantly ( $P < 0.05$ ) and positively correlated between carers and consumers and within these groups.

There were no significant differences found between mean scores on the survey responses for family/carers recruited via the hospital or community. The only significant difference between consumers recruited via the hospital or community was that consumers in the community had a higher mean scores (6.1 vs 4.7) for the statement 'My family initiated contact with mental health services' ( $t = 2.472$ ,  $d.f. = 125$ ,  $P < 0.05$ ). There were no significant differences in the means of family/carer responses in the hospital or community although community responses were marginally more positive on all items except on 'We initiated contact with mental health services' (see Table 4).

### Observations on the audit

Over the course of the project, the researchers made notes relating to their observations. Some of these are germane to the interpretation of the results and might be considered findings in their own right.

The documentation of care in the community files was typically poor. Despite reviewing 3 months of community notes (or the equivalent of 13.5 years of care), there was very little documentation at all. The notes in both the

inpatient and community files tended to describe individual symptoms or crisis events rather than the social world of the person. It appears that much of what occurs in relation to community care in particular goes undocumented.

Many people had multiple admissions to hospital or had been receiving case management services for prolonged periods of time. Sometimes the term 'Well known to mental health services' was used. In such cases, it was rare for staff to have any documented contact with family. For example, one man had more than 80 admissions to hospital and in the preceding five admissions there was no evidence of staff engaging with family or carers. In one sense this man was certainly 'well known to psychiatric services' as was frequently documented in the file. However, less clear was whether or not his family and/or social situation were as well known. This project provided the opportunity to talk to some of the family members of people who received the label of 'well known' and many described having less contact with mental health services over time (unless they initiated it).

There were examples discovered in the inpatient files of people repeatedly admitted to hospital in a great deal of distress following altercations or arguments at home. With few exceptions, the person was discharged when they became 'settled' and the pattern repeated itself shortly after. There were cases where a loss of a significant relationship, for example, a spouse or friend, appeared imminent or there had been a recent serious breakdown of communication between the consumer and family and the person was admitted principally with depressive symptoms. Rarely did the documentation of care confirm a belief other than that the problem rested principally with (or more often within) the consumer. In the files reviewed, there were no documented examples of shared counselling being offered to the affected parties from within the service (although some were referred to external agencies).

### Limitations

These results need to be considered cautiously for a number of reasons. While the files for audit were selected randomly and appeared to be quite representative of the 'typical' profile of inpatient and case managed person in the community, the sample sizes are small. The auditor was aware of the introduction of practice standards and was integral in promoting them. Strictly applied operational definitions and supervision assisted in reducing resulting bias that this awareness may have caused. The lack of control group, open nature of the evaluation, and after-only surveys mean that a number of factors may

**TABLE 4:** Responses to family/carer surveys

	1. Mental health workers consulted family/carers as they planned services and medication.	2. Mental health workers were interested in what family/carers could tell them.	3. Mental health workers gave detailed information about illness to family/carers.	4. Family/carer involvement enhanced care and treatment.	5. Family/carers were provided with useful information about where they could obtain help and support.	6. I was satisfied with the level of involvement of family/carers during this admission/period.	7. Family/carers initiated contact with mental health services.	8. Family/carers had their questions answered satisfactorily by mental health workers.
Hospital consumer survey (n = 41)†								
Mean	6.3	6.3	5.8	7.1	5.8	6.6	6.1	5.7
SD	2.7	2.9	3.3	2.8	3.2	2.8	3.1	2.8
% > 5	73%	68%	56%	83%	63%	78%	61%	56%
Hospital family survey (n = 27)								
Mean	6.9	6.9	6.3	8.1	5.7	6.5	6.3	6.8
SD	3.0	3.0	2.1	1.9	2.5	2.7	2.4	2.5
% > 5	52%	74%	67%	89%	59%	70%	74%	78%
Community consumer survey (n = 86)								
Mean	5.7	5.7	5.6	6.5	5.5	6.9	4.7	5.8
SD	2.8	2.6	2.4	2.6	2.2	2.3	2.7	2.3
% > 5	50%	59%	53%	67%	52%	77%	44%	57%
Community family survey (n = 33)								
Mean	6.4	7.4	6.7	8.3	6.5	6.8	5.9	6.9
SD	2.6	1.9	2.3	1.4	2.3	2.2	2.0	2.1
% > 5	61%	85%	70%	94%	67%	70%	70%	79%

† Individuals rated each item from 1 to 10 where 'Strongly disagree' was coded 1 or 2, 'Disagree' 3-5, 'Agree' 6-8, and 'Strongly agree' 9 or 10. SD, standard deviation.

have influenced the final results. For example, there was an improvement in the completion of outcome measures and in the formulation of treatment/care plans during the course of the project, so other related quality improvement activities may have impacted on the findings. The Hawthorne effect, that is, impact of being observed, may have also contributed to observed improvements.

## DISCUSSION

The file audit can inform us with some confidence of differences in documented contact between health professionals and families before and after introduction of practice standards. Notwithstanding the limitations of the study, modest and consistent improvements in documented carer involvement over the course of the project were found. There were substantial increases in documented formal contact between carers and mental health practitioners and evidence of collaborative care planning in the acute inpatient setting, but little difference in documented practice in the community setting. Because of the after-only nature of the carer and consumer surveys, it cannot be inferred that the introduction of the practice standards themselves made a difference to people's perceptions. These surveys do, however, reveal a cross-section of experience, the perceived strengths and weaknesses of the service at the time, and suggest particular elements of participation that might be related to satisfaction with care.

The frequency of documented contact may be tenuously related to the perceived quality of participation by consumers and carers. Good, bad, and indifferent interaction between health professionals, carers, and consumers may go undocumented. This may be particularly so in community settings where the file may not be reviewed or shared with others very frequently. Health professionals may also have difficulty accounting for interaction unless they can be said to have provided some specific intervention or received some particularly noteworthy information.

Consumers and carers were generally satisfied with the level of involvement of carers in mental health care even though there was only modest agreement that mental health workers consulted family or carers. The practice standards themselves were inconsistently applied, but the survey findings lend support for them in principle with the key elements of the practice standards, that is, collaboration and information sharing being strongly correlated with satisfaction with involvement for both consumers and carers.

There was less overall satisfaction with involvement of carers in the inpatient setting despite more documented involvement. This may be because admission to acute units typically occurs during a crisis period for both the consumer and family. Friedmann *et al.* (1997) observed that regardless of diagnosis, having an acutely unwell family member disrupts family functioning. Caring for someone with a mental illness can cause considerable burden in terms of distress and carers seldom feel that their own support needs are met by psychiatric services (östman *et al.* 2005; Saunders 2003). Clearly this service (and others) could do more to provide direct support to families in crisis and to disseminate information about available supports. The practice standards perhaps reflect the view of the family or carer as informant and collaborator instrumental in the care and treatment of the person with mental illness. This view needs to be complimented with a view of the family or carer in distress or with shared problems and related needs for support and care.

The practice standards do not prescribe who ought to make initial contact with family members or carers, or indeed who ought to seek permission from service users for contact. In the absence of a prescriptive approach, practitioners may make unfounded assumptions that others have or will make contact. This warrants the consideration of a named practitioner being the principle carer liaison person with each active consumer of mental health services. In the inpatient unit, there was a statistically significant increase in the number of contacts between medical staff and families and the number of families involved in a formal way in treatment planning. It appears that medical staff were one group who accepted responsibility for coordinating one facet of liaison with families, that is, involvement in formal treatment planning, thus realizing an important purpose of the practice standards.

Whether the positive changes outlined in this paper relating to family participation are sustained or improved further is likely to depend on how new staff are introduced to the standards and the maintenance of positive role models in practice. The casualization of the workforce and rapid turnover of staff is a challenge to communicating generally (Batch *et al.* 2006) and contributes to carer fatigue (Taylor & Barling 2004). Those employed on casual or short-term contracts are unlikely to have the same commitment to and identification with the workplace as those with more secure tenure (Veenstra *et al.* 2004). However, practice standards can indicate clear expectations of all staff regardless of tenure and assist in embedding inclusive, respectful carer-friendly practice in the culture of mental health services.

## CONCLUSIONS

This project arose from expressed concerns by families that their knowledge about their family member with mental illness in times of crisis was not solicited, acknowledged, or held in regard by health professionals. Since the introduction of these standards, specific carer's recognition legislation has been passed in several states in Australia. Practice standards may be one feasible method to tangibly demonstrate compliance with such legislation. Data from this project highlight improvements in the degree to which family/carers are involved in Townsville Integrated Mental Health Services. A large majority of respondents agreed that mental health professionals were interested in what they had to say. However, the findings by no means provide confidence that all families have or will be engaged with mental health services to the extent that their needs and the needs of consumers are met.

The practice standards were found to be largely well received, not difficult to apply, but inconsistently attended to. Ideally, health professionals will engage with families without any conscious consideration of practice standards or legislation. Ideally they will do so because it is the right thing to do, from an ethical and professional point of view and in their interests and the best interests of consumers. Such integration of family/carer engagement may be the modus operandi of some individual practitioners, but a cultural change needs to occur in order that it becomes the norm and for it to be seen as essentially helpful to all. The utilization of practice standards shows some promise in improving the quality of carer participation.

## ACKNOWLEDGEMENTS

This project was made possible by sponsorship from Queensland Health, the energy and enthusiasm of steering group over the life of the project and the participants who generously shared their experiences. The steering group included the following people: Dr John Allan, Peter Edwards-Davis, Jill Edwards-Davis, Barbara Dennis, Andy Frogatt, Desley Gray, Phillipa Harris, Walter Humphreys, Graham Smalley, Lyn Tyson, Marilyn Voss, and Kate Young. Members were drawn from the Townsville Mental Health Service, the Townsville Consumer Advisory Group, Carers Queensland, The Migrant Resource Centre, the Mental Illness Fellowship of North Queensland, The Association of Relatives & Friends of the Mentally Ill, and the Queensland Department of Premiers.

## REFERENCES

- Batch, M., Barnard, A. & Windsor, C. (2006). Nursing communication and casualisation of the nursing workforce. *Australian Nursing Journal*, 14 (3), 33.
- Biegel, D. E., Song, L. & Milligan, S. E. (1995). A comparative analysis of family caregivers' perceived relationships with mental health professionals. *Psychiatric Services*, 46 (5), 477–482.
- Bustillo, J., Lauriello, J., Horan, W. & Keith, S. (2001). The psychosocial treatment of schizophrenia: An update. *American Journal of Psychiatry*, 158 (2), 163–175.
- Cleary, M., Freeman, A. & Walter, G. (2006). Carer participation in mental health service delivery. *International Journal of Mental Health Nursing*, 15 (3), 189–194.
- Commonwealth of Australia. (1996). *National Standards for Mental Health*. Canberra, ACT: Commonwealth Department of Health and Aged Care.
- Friedmann, M. S., McDermut, W. H., Solomon, D. A., Ryan, C. E., Keitner, G. I. & Miller, I. W. (1997). Family functioning and mental illness: A comparison of psychiatric and nonclinical families. *Family Process*, 36 (4), 357–367.
- Hodgson, O., King, R. & Leggatt, M. (2002). Carers of mentally ill people in Queensland: Their perceived relationships with professional mental health service providers: Report on a survey. *Australian E-Journal for the Advancement of Mental Health*, 1 (3), 1–15.
- Jakobsen, E. S. & Severinsson, E. (2006). Parents' experiences of collaboration with community healthcare professionals. *Journal of Psychiatric and Mental Health Nursing*, 13 (5), 498–505.
- Karp, D. A. (2001). *The Burden of Sympathy: How Families Cope with Mental Illness*. New York: Oxford University Press.
- Lakeman, R. (2008). Family and carer participation in Mental Healthcare: Perspectives of consumers and carers in hospital and home care settings. *Journal of Psychiatric and Mental Health Nursing*. (In Production).
- McFarlane, W. R. (1997). Fact: Integrating family psychoeducation and assertive community treatment. *Administration and Policy in Mental Health*, 25 (2), 191–198.
- McFarlane, W. R., Dushay, R. A., Deakins, S. M. *et al.* (2000). Employment outcomes in family-aided assertive community treatment. *American Journal of Orthopsychiatry*, 70 (2), 203–214.
- Mental Health Council of Australia and Carers Association of Australia (2000). *Carers of People with Mental Illness – Final Report*. Canberra, ACT: Commonwealth Department of Health and Aged Care.
- Mithalopoulos, C., Magnus, A., Carter, R. & Vos, T. (2004). Assessing cost-effectiveness in mental health: Family interventions for schizophrenia and related conditions. *Australian and New Zealand Journal of Psychiatry*, 38, 511–519.
- Östman, M., Wallsten, T. & Kjellin, L. (2005). Family burden and relatives' participation in psychiatric care: Are the

- patient's diagnosis and the relation to the patient of importance? *International Journal of Social Psychiatry*, 51 (4), 291–301.
- Saunders, J. C. (2003). Families living with severe mental illness: A literature review. *Issues in Mental Health Nursing*, 24 (2), 175–198.
- Sherman, M. D., Faruque, H. D. & Foley, D. D. (2005). Family participation in the treatment of persons with serious mental illness. *Psychiatric Services*, 56 (12), 1624–1625.
- Taylor, B. & Barling, J. (2004). Identifying sources and effects of carer fatigue and burnout for mental health nurses: A qualitative approach. *International Journal of Mental Health Nursing*, 13 (2), 117–125.
- Veenstra, K., Haslam, S. A. & Reynolds, K. J. (2004). The psychology of casualization: Evidence for the mediating roles of security, status and social identification. *British Journal of Social Psychology*, 43 (4), 499–514.