2	**EMPOWERMENT**

To encourage full and genuine participation by users and carers in all aspects of mental health services including planning and commissioning.

National Service Framework: key action 5

Raising the standard. Cardiff: Welsh Assembly Government, October 2005

By the end of December 2009, service users and carers are to have timely access to comprehensive, clear, appropriate and helpful information, in a range of appropriate formats and languages. [Key action 5 paragraph 12.4]

Is there any evidence regarding the use of information already available?

What information is helpful for users/carers?

See also 6.22 for psychoeducation

The *statements* | The *evidence*

2.1 Providing information about patients' illness

2.1a Health professionals should provide **accessible information** about **schizophrenia** and its treatment to service users and carers; this should be considered an essential part of the routine treatment and management of schizophrenia. When talking to services users and carers, health professionals should avoid using clinical language or keep it to a minimum. Where clinical language is used, service users and carers should have access to written explanations. All services should provide written material in the language of the service user, and interpreters should be sought for people who have difficulty in speaking English. [i]

Patients and, where appropriate, families and carers should be provided with information on the nature, course and treatment of **eating disorders**[ii]**, depression**[iii]**, panic disorder or generalised anxiety disorder**, including the use and likely side-effect profile of **medication** [iv]. When talking to patients and carers, healthcare professionals should use everyday, jargon-free language. If technical terms are used they should be explained to the patient. Where possible, all services should provide written material in the language of the patient. Where available, consideration should be given to providing psychotherapies and information about medications in the patients own language if this is not in English. [iii,iv]

i. National Institute for Clinical Evidence. *Schizophrenia. Core interventions in the treatment and management of schizophrenia in primary and secondary care.* Clinical guideline – No. 1. London: NICE, December 2002. Review date: December 2006 **http://www.nice.org.uk/pdf/CG1NICEguideline.pdf** [accessed 29/07/05]
(Evidence based guideline with systematic literature search and expert consensus.)

ii. National Institute for Clinical Excellence. *Eating disorders. Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders.* Clinical guideline No. 9. London: NICE, January 2004. Review date: January 2008 **http://www.nice.org.uk/pdf/cg009niceguidance.pdf** [accessed 29/07/05]
(Evidence based guideline with systematic literature search and expert consensus.)

iii. National Institute for Clinical Excellence. *Depression. Management of depression in primary and secondary care.* Clinical guideline No. 23. London: NICE, December 2004. Review date: December 2008 **http://www.nice.org.uk/pdf/CG023NICEguideline.pdf** [accessed 29/07/05]
(Evidence based guideline with systematic literature search and expert consensus.)

iv. National Institute for Clinical Excellence. *Anxiety. Management of anxiety (panic disorder with or without agoraphobia, and generalised anxiety disorder) in adults with primary, secondary and community care.* Clinical guideline No. 22. London: NICE, December 2004. Review date: December 2008 **http://www.nice.org.uk/pdf/CG022NICEguideline.pdf** [accessed 29/07/05]
(Evidence based guideline with systematic literature search and expert consensus.)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

2 | EMPOWERMENT

<table>
<tr><td>The *statements*</td><td>The *evidence*</td></tr>
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2.1b Although many patients would like to know the truth, the rights of those who do not wish to know should also be respected. Therefore the diagnosis of mental disorder should not be **routinely disclosed**, but mental health professionals should take into consideration their **patients' preferences** and act appropriately to their choice. The results have shown that 80% of the patients received some information about their illness and 37% of the participants had satisfactory insight. However only 46% of the participants declared that they wished to know what was wrong with them.[i]

Caveat: The results of this study are based on a small sample size.

i.   Marzanski M. What have you been told about your illness? Information about diagnosis among psychiatric inpatients. *International Journal of Psychiatry in Clinical Practice* 2002; **6**: 103-106

(Type IV evidence - cross-sectional survey among psychiatric inpatients, to explore what they believe is wrong with them, what they have been told and by whom, and what they wish to know about their illness. 35 out of 53 inpatients present on 30 November 2000 in 3 acute wards in a psychiatric hospital in Coventry participated.)

2.1c The **selectivity of information** given to patients appears to reflect the **doctors perception** of what is important. This might not correlate with what the patient may wish to be told. Discussions with patients about side-effects may need to be more comprehensive than they currently are. Overall, doctors said they gave large amounts of information to patients about possible side-effects of anti-psychotic drugs, but some side-effects were discussed far more frequently than others (e.g. dry mouth (94.2%), blurred vision (92.5%), parkinsonism, akathisia (96.8%) and weight gain (84.3%) were the most side effects discussed without patients having to ask.[i]

Caveat: The response rate was low with only 121 questionnaires (59%) being returned. The habits of non-respondents may be different to those who replied.

i.   Smith S. What you don't know won't hurt you: information given to patients about the side-effects of antipsychotic drugs. *Psychiatric Bulletin* 2000; **24(5)**: 172-174

(Type IV evidence – cross-sectional study in which all doctors working clinically at a large mental health trust in south London, were surveyed by anonymous questionnaire on whether they inform their patients about the side effects of antipsychotic medication.)

2.1d Two-thirds (65%) of patients did not know the purpose of their medication; only 10% knew about the side-effects. Longer length of stay, older age and voluntary status were associated with less knowledge. Despite **poor knowledge**, most patients accepted their treatment. However, few realised that they had any choice. The prevalence of true informed consent is low among this group and raises issues about patients' rights.[i]

i.   Billcliff N, McCabe E, Brown KW. Informed consent to medication in long-term psychiatric in-patients. *Psychiatric Bulletin* 2001; **25**: 132-134

(Type IV evidence - cross-sectional study of 68 detained and voluntary long-term psychiatric in-patients (59% male, 65% over 50 years old) on 3 wards at Bellsdyke hospital, Scotland. Semi-structured interviews were undertaken to examine inpatients knowledge and attitudes towards their medication.)

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2.1e Due to methodological limitations and insufficient reporting, the results of available studies on **patient education** in schizophrenia are far from conclusive. The demonstration of the efficacy of patient education in improving **knowledge and compliance** is most consistent. [i]

i. Merinder, L. Patient education in schizophrenia. *Acta Pychiatrica Scandinavica* 2000; **102**: 98-106

(Type V evidence – literature review of 7 randomised controlled trials of patient education in patients with schizophrenia, and 4 naturalistic studies. 8 randomised controlled trials of patient education in mixed samples were used as supplementary information.)

Delivery of information

2.1f The **computer based patient education** offered no advantage over sessions with a **community psychiatric nurse**. Investigation of computer use combined with other health service contacts would be worthwhile. Rates of completion of intervention did not differ significantly. Computer sessions were shorter than sessions with nurse (14-minutes versus 60-minutes). More patients given nurse based education thought the information relevant. Of 20 patients in combination group, 13 preferred the sessions with the nurse and seven preferred the computer. There were no significant differences between groups in psychological outcomes. Because of the need to transport patients to the computer for their sessions, there was no difference between interventions in costs, but computer sessions combined with other patient contacts would be substantially cheaper. [i]

Caveat: The follow-up was only 59.8%.

i. Jones RB, Atkinson JM, Coia DA, et al. Randomised trial of personalised computer based information for patients with schizophrenia. *British Medical Journal* 2001; **322(7290)**: 835-840

http://bmj.bmjjournals.com/cgi/content/full/322/ 7290/835 [accessed 29/07/05]

(Type II evidence – randomised controlled trial of 112 patients with schizophrenia in contact with community services in Glasgow (aged 18 -65 yrs, 67% male). Patients were assigned to computer intervention combining patient's medical record with general information about schizophrenia (n=56); sessions with a community psychiatric nurse (n=28) or a "combination" (n=28). 3 months follow up.)

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2.1g The **quality of information on the Internet** produced by an Internet search was quite low. For-profit Web sites appeared much more frequently than not-for-profit sites among the first 20 sites generated by each search engine, and they contained poorer information. The search generated a total of 178 active sites. Overall, the quality of information was poor. Only half of the sites mentioned any DSM-IV diagnostic symptom or criteria in their descriptions of depression, and only a quarter listed 11 to 14 symptoms or criteria. Almost half of the sites made no mention of medications, psychotherapy, or professional consultation as suggested treatments for depression.[i]

i. Lissman TL, Boehnlein JK. A critical review of internet information about depression. *Psychiatric Services* 2001; **52**: 1046-1050

http://psychservices.psychiatryonline.org/cgi/reprint/ 52/8/1046 [accessed 29/07/05]

(Type IV evidence – survey of the quality of information about depression available on the Internet. Websites generated from major Internet search engines were rated by whether it mentioned the 9 symptoms and 5 major criteria of a major depressive episode and whether it made any of 3 basic treatment recommendations.)

2.1h **Telephone health-line** providers should be aware that many callers appear to interpret advice to seek additional health care differently than intended. Findings suggest the need for continuing quality control interventions to **reduce miscommunication**, insure better understanding of advice by callers, and contribute to more effective service. Overall disagreement between the nurses and callers was 27% (12% by false positive and 15% by false negative) and kappa is 0.45. Characteristics such as living alone (adjusted OR = 2.5), and calls relating to psychological problems (OR = 2.6), were associated with inaccurate reports.[i]

See also sections 4.3 – 4.4

i. Leclerc B-S, Dunnigan L, Cote H, Zunzunegui M-V, Hagan L, Morin D. Callers' ability to understand advice received from a telephone health-line service: comparison of self-reported and registered data. *Health Services Research* 2003; **38**: 697-710.

(Type IV evidence - secondary analysis of data from a cross-sectional survey in 1997 of 4,696 randomly selected users of a free telenursing health-line service available in Quebec. Self-reported advice from follow-up survey phone interviews after the participant's call were compared to the data consigned by the nurse in the computerized call record. 174 callers had a psychosocial problem.)

2 | EMPOWERMENT

National Service Framework: key action 6

Raising the standard. Cardiff: Welsh Assembly Government, October 2005

A range of appropriate independent, trained, and dedicated advocacy services should be available and promoted across Wales. [Key action 6 paragraph 13.1]

What evidence is available on how advocacy can be delivered?

What are the benefits of providing advocacy services in the community?

The *statements*   The *evidence*

2.2 Delivering advocacy

2.2a Compared with routine rights advocacy, the **experimental advocacy** based on patients' needs and best interests, which was maintained throughout the patients' involuntary hospitalisation, significantly improved patients' and staff members' experience of **involuntary treatment**. Better compliance with aftercare among patients receiving personal advocacy led to a statistically and economically significant reduction in **rehospitalisation**. At the start of hospital care, satisfaction with care was similar in both groups; however, it improved significantly in the experimental group (mean scores from 16 ± 7.3 to 18 ± 6.4, p=0.001) while it declined in the control group (from 15.5 ± 8.5 to 14.7 ± 8.9). Aftercare attendance was significantly better in the experimental group than in the control group (means of 1.6 ±0.7 and 1.2 ±0.8 p=0.01, respectively). The experimental subjects' risk of involuntary rehospitalisation was less than half the risk of control subjects, and **community tenure** was significantly increased. Clinical staff reported that the experimental advocacy facilitated management of patients.[i]

i. Rosenman S, Korten A, Newman L. Efficacy of continuing advocacy in involuntary treatment. *Psychiatric Services* 2000; **51**: 1029-1033

http://psychservices.psychiatryonline.org/cgi/reprint/ 51/8/1029 [accessed 29/07/05]

(Type III evidence – non-randomised experimental study of 105 involuntarily hospitalized psychiatric inpatients in Canberra, Australia. 53 consecutive patients received personal advocacy from hospital entry until discharge and 52 consecutive patients in a control group received routine rights advocacy from entry through the commitment hearing only.)

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2.2b The study found that **Community Psychiatric Nurses** (CPNs) have a crucial role to play in the care, support and empowerment of people with enduring mental disorder (PEMD). The results indicate that **CPNs work in an empowering way** with PEMD and in doing so they manage the dual tensions of responsibility to the patient as client and accountability to the organisation. 'Sustaining relationships' with PEMD were the central vehicle through which the needs of service users were met. This was stressed by both CPNs and PEMD. It was revealed that CPNs work with PEMD helps the clients deal with rights and responsibilities within the wider setting of the community, and that providing medication, support, liaison and active help. CPNs contribute to PEMDs ability to participate in the community and play a valuable part in promoting public health and social inclusion.[i]

Caveat: It is difficult to determine whether the results are reliable due to the limited reporting of raw data and methods of data analysis.

i. Tilley S, Pollock L. *Community psychiatric nurses' empowerment of people with enduring mental disorder in the community. Involving users to develop services: final report*. Edinburgh: University of Edinburgh, 2000.

(Type IV evidence – observational study with both qualitative and quantitative measures. 21 Community Psychiatric Nurses (CPNs) and 3 Health Care Assistants (HCAs) in Scotland were interviewed. Quantitative and qualitative measures were also taken with the CPNs' consenting clients i.e. people with enduring mental disorder (PEMD). 49 PEMD completed first stage of quantitative measures, 14 took part in Client Interview 1, and 10/14 were interviewed at Client Interview 2.)

2.2c In the course of 5 sessions in 3 years, 160 consumers and family members graduated from the **Leadership Academy**. In a 27 month period, graduates took 1,345 action steps to address issues of concern, with 400 outcomes, ranging from the establishment of a speakers bureau to starting a respite facility. The greatest level of advocacy work occurred in the areas of **community education** and **improving services**. Participants ranked **networking** with consumers and family members (chosen by 34% subjects), and support and confidence building (19%) as the most valuable aspects of the academy. 66% respondents rated the usefulness of the academy as very useful. 41% participants stated their sense of empowerment had greatly increased as a result of the academy. [i]

Caveat: Low response rate to surveys (46%). Procedures for data interpretation were unclear, and there was insufficient data collected available for independent assessment.

i Hess RE, Clapper CR, Hoekstra K, Gibison FP. Empowerment effects of teaching leadership skills to adults with a severe mental illness and their families. *Psychiatric Rehabilitation Journal* 2001; **24**: 257-265

(Type IV evidence - qualitative study engaging graduates from a Leadership Academy in Idaho. 5 Academy sessions teaching basic skills for adults with a mental illness and family members to become effective leaders in advocacy organisations, were offered over 2 years. Data were collected on advocacy actions and outcomes through monthly telephone calls and quarterly interviews with academy participants for 27 months. Of the 97 participants surveyed, 45 responded.)

2 | EMPOWERMENT

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2.2d For **empowerment** to occur, clients need psychiatric stability and decision-making skills. Organisations promote empowerment by ensuring that clinical staff have the time to involve clients in treatment planning, promoting staff attitudes that are respectful of clients' ability to participate in **treatment planning**, providing clients with a range of treatment options, designing programmes that have a strong philosophical commitment to client empowerment, and implementing programmes properly.[i]

Caveat: It is unclear how the themes were identified from the focus groups and there is insufficient data available for independent assessment. Clients were paid $3 for participating in the focus groups.

See also Section 2.4 for further information on involving patients in mental health services

i. Linhorst DM, Hamilton G, Young E, Eckert A. Opportunities and barriers to empowering people with severe mental illness through participation in treatment planning. *Social Work* 2002; **47**: 425-434

(Type IV evidence - qualitative study reviewing documents and conducting focus groups with clients and staff of a public psychiatric hospital in America. 72 of 208 clients (35%) present in the facility and 114 of 389 staff (29%) participated.)

2.2e Findings from focus groups indicate personal need for **education and skills** related to decisions about their Americans with Disabilities Act (ADA) rights, job accommodations, disclosure and negotiation. Authentic empowerment emerges when practioners replace their job and maintenance perspective with a **teaching, skills development and peer support perspective** to achieve independent career decision making over long term.[i]

Caveat: The description of the method of data collection given and the procedures for data analysis was limited.

i. Granger B. The role of psychiatric rehabilitation practitioners in assisting people in understanding how to best assert their ADA rights and arrange job accommodations. *Psychiatric Rehabilitation Journal* 2000; **23**: 215-223

(Type IV evidence - qualitative study of 20 focus groups to learn about the experiences of people with psychiatric illness in America using job coaches or job developers and others not using those services. There were 78 participants in the focus groups who used job coaches and 59 participants in separate focus groups who did not use coaches.)

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2.2f As a result of the study a draft list of 48 competencies was developed that support **rehabilitation and empowerment** in individuals with severe mental illness. Of these, 35 were rated by panel members as having a very important effect on outcomes. The competencies focused on 7 themes: clinician-client relationship, initial and ongoing assessment, rehabilitation and empowerment, treatment, family and support system, social and cultural factors and resources and coordination of care. This project demonstrates that it is possible to develop a core competency set that can be strongly supported by diverse groups of stakeholders. These competencies may be useful in clinician training, recruitment, and credentialing efforts.[i]

Caveat: Sequences from the original data and information collected is not presented for independent assessment.

i. Young AS, Forquer SL, Tran A, Starzynski M, Shatkin J. Identifying clinical competencies that support rehabilitation and empowerment in individuals with severe mental illness. *Journal of Behavioural Health Services and Research* 2000; **27(3)**: 321-333

(Type IV evidence - qualitative study in Colorado and New Mexico reviewing existing literature and competency statements, and focus groups and interviews with clients, family members, clinicians, managers, experts, and advocates. Representatives from each of these groups participated in a national panel and used a structured process to identify 37 final competencies.)

2.2g An **improved dialogue** is needed with mental heath providers, public administrators, mental health policy makers, mass media and politicians. The dialogue between primary care team and the specialist must also be improved. A **global alliance** for action is needed to ensure better and more available services to those who suffer from mental disorders. The findings indicate that the Mental Illness Advocacy Movement is very alive and in full growth. Its role in the management of the mentally ill has become more and more important over the years. In several countries, it makes it possible to overcome some of the deficiencies of the National or Private Health Services. Thanks to the actions of the various **Mental Illness Advocacy Groups**, today, patients and families are more and better informed of their conditions and their rights. In many cases, this results in earlier diagnosis, better compliance and better outcomes. However, despite significant improvement in the status of the mentally ill patient, much still remains to be done.[i]

i. Morselli PL. Present and future role of Mental Illness Advocacy Associations in the management of the mentally ill: realities, needs and hopes at the edge of the third millennium. *Bipolar Disorders* 2000; **2**: 294-300

(Type V evidence – literature review of the development and current status of the Mental Illness Advocacy Movement in the USA and in Europe. A literature search was conducted and several personal inquiries and contacts made with different Mental Illness Advocacy Groups in the USA and in Europe.)

2 | **EMPOWERMENT**

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2.3 **Staff and patient perspectives on advocacy**

2.3a There was overwhelming support for patients having **access to an advocacy service**. 98% of staff and patients agreed that advocacy is needed in high security hospitals. Ashworth CAB Patients Advocacy Services (ACPAS) is well known by patients and staff. 93% of patients knew about the services and 78% had used it. Staff welcomed the use of ACPAS to support patients in exerting their citizen rights and issues of daily living, but regretted the close association between advocacy and complaints. Patients valued the support of advocates over issues of their care and treatment, especially in connection with medication, their care plan, attendance at review meetings and tribunals. Many staff, nurses in particular were strongly opposed to this involvement and believed advocates have no role in clinical issues.

Community meetings were found to be largely successful and discredited by patients and staff. Patients rated very highly the advocates ability to listen, understand their point of view and provide them with accurate information. Indications of the impact of advocacy include: patients were felt to benefit from advocacy although some had reservations. Over 66% of patients and staff felt that advocacy gives patients a voice. 79% of patients and 59% of staff felt advocacy raises staff awareness of patients rights. Advocacy indirectly helps staff through helping patients.

Relatives of patients were very positive about the advocacy service, valuing it for its independence and hard work on behalf of the patients.[i]
Caveat: There was limited information on how the data-analysis was conducted and very little raw data available for independent assessment.

i. Barnes D, Tate A. *Advocacy from the outside inside. A review of the patients' advocacy service at Ashworth Hospital*. Durham: Durham University, 2000

(Type IV evidence - qualitative study involving 65 patients and 53 staff to develop an understanding of Ashworth CAB Patients Advocacy Services. This study was part of an informative review of services at Ashworth consisting of 4 parts: review of literature, understanding of ACPAS and its setting (qualitative study), and reviewing work done (relevant documents, and examining process of outcomes).)

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2.3b This study shows the potential of health professionals to empower people with enduring mental ill health, by attending to the quality of communication and continuity of care they provide and to where this takes place. It further underlines a need to address the **social stigma and exclusion** this group experiences. The primary goal of the responders was to enhance, sustain, and take control of their mental health. The building of positive therapeutic relationships with professionals based upon effective communication, trust, and continuity were important to achieving this aim. However, the settings in which their health care took place could affect responders' attempts to deal with social stigma. Experiences of social isolation, socioeconomic privation, and stigmatisation were often pervasive. These compromised responders' opportunities and their capacity to enhance their mental health, compounding their illness and marginalisation.[i]

i. Kai J, Crosland A. Perspectives of people with enduring mental ill health from a community-based qualitative study. *British Journal of General Practice* 2001; **51(470)**: 730-736

(Type IV evidence - community-based qualitative study of 32 responders registered with 4 general practices in the UK, serving 5 wards with a mean Townsend Deprivation Score of 7.75.)

2.3c While mainstream service definitions would place advocacy as a distinct service, black projects saw most of their work as advocacy. The urgent need for decent services for **minority communities** combined with extremely limited funding meant that more fundamental services (housing, information and support) were likely to be prioritised over an **advocacy service**. The authors suspect that low expectations among excluded and disempowered communities is informal and involuntary; it is regarded as part of the parcel of being a good community member, or as an expression of faith and its values in helping.
Recommendations outline key issues including: funding, black and ethnic service user and carer involvement, language and communication, and culturally appropriate advocates.[i]
Caveat: Service users and carers were each paid £50 to take part in a face-to-face interview.

i. Rai-Atkins A, Jama AA, Wright N, et al. *Best practice in mental health. Advocacy for African, Carribean and South Asian communities.* Bristol: Policy Press, 2002

(Type IV evidence - qualitative study reviewing existing literature and gathering information from 12 advocacy projects providing a service to African, Carribean and South Asian Communities. The authors spoke to 35 service users and carers within the region, facilitated 6 workshops, and made presentations at 2 national conferences. In total 142 users, carers, advocates and professionals were consulted.)

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The *statements*	The *evidence*

2.3d Two important and very different issues were of concern to those who were consulted, whether they were service users or those caring for and working with service users. These were: benefits in their broadest sense, and **formal contact with mental health professionals** such as **Care Programme Approach** and Multi-discipline team meetings, consultant appointments etc. It was also clear that there were many organisations in Sheffield already providing advocacy services for their clients, which were very valued. However the present system was one which had grown up by default, and was fragmented, often provided by insecurely funded projects, with difficulties of continuity, and was not always easy to access.[i]

i. Coleman C, Dunmur J. *Surveying mental health advocacy needs in Sheffield*. Sheffield: Sheffield Community Health Council, 2001

(Type IV evidence - qualitative study gathering different points of view on advocacy needs in Sheffield using a variety of methods: questionnaire (199 readers of 'Your Voice' magazine, targeted user groups), interviews (40 statutory, voluntary and community service providers.), focus groups (8 mental health users/survivors) and a personal narrative commissioned from a service user.)

2.3e In general, there was poor understanding of the **background and training of advocates**, and their Code of Practice. There were also important differences in the way in which different groups of staff saw advocacy, with **CPNs** having the best understanding. Experiences of advocacy were positive and it was seen as being helpful both for clients and staff, despite fears that advocates might work to their 'own agendas'. There is a need to improve psychiatrists' understanding of what advocacy is, through the involvement of advocates and service users in their training. This would help to allay their anxieties about the role of advocates.[i]

Caveat: Only one researcher analysed the data collected, and there is little data available for independent assessment.

i. Lacey Y, Thomas P. A survey of psychiatrists' and nurses' views of mental health advocacy. *Psychiatric Bulletin* 2001; **25:** 477-480

(Type IV evidence - qualitative study of interviews with 5 senior house officers, 5 staff nurses and 4 community psychiatric nurses (CPNs) in Bradford, to determine how much doctors know about peer advocacy and their attitudes towards it. A full-time advocate was also interviewed to establish his views about how well staff understood his role.)

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2 | EMPOWERMENT

National Service Framework: key action 7

Raising the standard. Cardiff: Welsh Assembly Government, October 2005

To encourage full and genuine participation by users and carers in all aspects of mental health services including planning and commissioning.[paragraph 12.2]

How best can user and carer participation in mental health services be encouraged and achieved?

By March 2006 in line with 'Stronger in Partnership', the NHS and Local Authorities must have introduced arrangements to ensure constructive user and carer participation in the planning, design, delivery, and monitoring and evaluation of mental health services. [Key action 7 paragraph 13.2]

Which steps of the design, delivery, and monitoring and evaluation of mental health services will prove most beneficial for users and carers to be involved in?

What evidence exists to suggest that participation helps improve services?

The *statements*   The *evidence*

2.4 Encouraging user/carer participation in all aspects of mental health services

2.4a Users can be involved as employees, trainers, or researchers without detrimental effect. Involving users with severe mental disorders in the **delivery and evaluation of services** is feasible. Half of the studies considered involving users in managing cases. Involving users as employees of mental health services led to clients having greater satisfaction with personal circumstances and less hospitalisation. Providers of services who had been trained by users had more positive attitudes toward users. Clients reported being less satisfied with services when interviewed by users.[i]

Caveat: The review is limited by the quality of the included trials (small samples, few standardised unmodified measures). Key papers may have been missed as only English language studies were sought.

i. Simpson, EL, House AO. Involving users in the delivery and evaluation of mental health services: systematic review. *British Medical Journal* 2002; **325(7375)**: 1265-1268

http://bmj.bmjjournals.com/cgi/reprint/325/7375/ 1265 [accessed 29/07/05]

(Type I evidence - systematic review of 5 randomised controlled trials and 7 other comparative studies. 8 studies focused on involving users as service providers mainly working as case managers in services for clients with severe mental illness. 2 studies looked at the effects of involving users as trainers, and 2 studies considered involving users as interviewers. Evidence of users planning services was sought but not identified Literature search to 2001.)

2 | EMPOWERMENT

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The *evidence*

2.4b There is evidence that a simple **prompt to attend clinic**, very close to the time of the appointment may encourage attendance, and a simple orientation-type letter, 24-hours before the clinic appointment, may be more effective than a telephone prompt. This simple intervention could be a more cost effective means of encouraging **compliance** at first attendance, but further research is needed.

It is not clear whether there is any real difference between attendance of those prompted by telephone one or two days before the appointment, and those given the standard appointment management system (RR missed appointment 0.84, 95%CI 0.7 - 1.1). Text-based prompts, a few days before the appointment day, did increase clinic attendance when compared with no prompt (RR missed appointment 0.6 95%CI 0.4 to 0.9, NNT 6 95%CI 2 - 14). Only one small study reported data on the combination of telephone and text-based prompts versus no prompt (RR missed appointments 0.7 95%CI 0.4 - 1.2). When telephone prompts were compared with text-based prompts, the latter, in the form of an 'orientation statement' may be somewhat more effective than the telephone prompt (RR missed appointments 1.9 95%CI 0.98 - 3.8).

One last study compared a standard letter prompt with a letter 'orientation statement'. Overall, results tended to favour the orientation statement approach rather than the simple letter prompting attendance but the results did not reach conventional levels of statistical significance (RR missed appointments 1.6 95%CI 0.9 - 2.8).[i]

Caveat: Results data of included studies are from 1983 (n=2) and 1988 (n=1). Introduction of mobile phones and email may under estimate effect of contact as accessibility to these formats has increased far greater than in the 1980's.

i. Reda S, Makhoul S. Prompts to encourage appointment attendance for people with serious mental illness. *The Cochrane Database of Systematic Reviews* 2001, Issue 2 **http://www.mrw.interscience.wiley.com/cochrane/ clsysrev/articles/CD002085/frame.html** [accessed 29/07/05]

(Type I evidence - systematic review of 3 randomised controlled trials (total participants =597) Prompts could be text-based, electronic, by telephone call, by personal visit, or could employ financial or other rewards. Databases were searched for literature published up to June 2000.)

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The *evidence*

2.4c Evidence supports the notion that **involving patients has contributed to changes in the provision of services** across a range of different settings. An evidence base for the effects on use of services, quality of care, satisfaction, or health of patients does not exist. Papers often described changes to services that were attributed to involving patients, including attempts to make services more accessible and producing information leaflets for patients. Changes in the attitudes of organisations to involving patients and positive responses from patients who took part in initiatives were also reported.[i]

Caveat: The review is limited by the low quality of included trials. Key papers may have been missed as only English language papers were included.

i. Crawford MJ, Rutter D, Manley C et al. Systematic review of involving patients in the planning and development of health care. *British Medical Journal* 2002; **325**: 1263-1265
http://bmj.bmjjournals.com/cgi/reprint/325/7375/1263 [accessed 29/07/05]
(Type IV evidence - systematic review of 40 observational studies (from 42 papers - 31 were case reports, 5 surveys, 3 examined the records of meetings and 3 described the findings of research papers). A range of services were included in the review; 12 of the papers covered mental health services. Literature search to 2001.)

2.4d 'Stronger in Partnership' is available electronically. The aim of this guidance is to provide advice and information on how to effectively involve people who use mental health services and their carers in the design, planning, delivery and evaluation of those services. The guidance is for all those concerned with mental health services including people in the statutory and voluntary sectors, commissioners and providers, and service users and carers.[i]

i. Mental Health Policy Wales Implementation Guidance. *Stronger in Partnership. Involving Service Users and Carers in the design, planning, delivery and evaluation of mental health services in Wales*. Welsh Assembly Government. September 2004
http://www.wales.nhs.uk/documents/mental_health_stronger_partnership.pdf [accessed 1/11/05]
(expert consensus guidelines)

2.5 Benefits from user/carer participation

2.5a Results suggest that detailed **mutual understanding** of the presenting complaints may be less important than agreement that the core problem is psychological, and that referral for psychological therapy is appropriate. Among 464 trial patients, 395 received therapy. Patient baseline problem formulations included significantly more items than GPs, who identified significantly more items than therapists.
Agreement levels varied according to a range of patient and professional variables. While those patients in complete agreement with their therapists about their main problem after assessment had lower average BDI scores at 12 months (9.7 versus 12.6, p=0.03) no other significant associations between the extent of agreement and clinical outcome were found. There were significant (but relatively weak) associations between agreement and aspects of patient satisfaction.[i]

i. Gabbay M, Shiels C, Bower P, Sibbald B, King M, Ward E. Patient-practitioner agreement: does it matter? *Psychological Medicine* 2003; **33(2)**: 241-251
(Type II evidence – part of a randomised controlled trial of brief psychotherapy for depression in general practices, examining patient-practioner agreement on core presenting complaints. 464 patients with depression (75% female, aged 18-79) were allocated to receive cognitive behaviour therapy (CBT), non-directive counselling (NDC) or usual GP care in Manchester and London. Those who did not accept random allocation were offered the chance to be randomised between CBT or NDC (130) or choose their preferred therapy (137). 215 patients were referred for CBT, 180 to NDC and 69 to usual GP care. Follow-up was at 4 and 12 months.)

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2.5b **Preference for a given therapy** is not a powerful moderator of effect in the psychological treatment of panic disorder. There were no differences at pretest between the two conditions on demographic or outcome measures. Outcome was assessed with measurements rating the panic frequency and severity of **agoraphobia, general anxiety and depression**. Both conditions improved significantly on nearly all ratings. There were no significant differences demonstrable between the two conditions on any of the outcome measures.[i]
Caveat: The study included a small sample of participants. Follow-up at 12 weeks was low (75.7%).

i. Bakker A, Spinhoven P, Van Balkom AJLM, Vleugel L, van Dyck R. Cognitive therapy by allocation versus cognitive therapy by preference in the treatment of panic disorder. *Psychotherapy and Psychosomatics* 2000; **69**: 240-243

(Type II evidence - randomised controlled trial in Amsterdam of 66 patients, 35 treated with cognitive therapy (CT) in a randomised placebo controlled clinical trial to compare the efficacy of paroxine, clomipramine and CT and 31 patients who had refused randomisation and received CT by preference.)

2.5c From the 151 patients who completed treatment results suggest that, patients who expect treatment to be effective tend to engage more constructively in session, which helps bring about symptom reduction. Alliance remained significant when controlling for expectancies (β =0.47, sr^2 = 0.20, t(148) = 6.33, p<0.01). None of the expectancy scales interacted with alliance ratings in the prediction of clinical improvement.[i]
Caveat: It is unclear whether the groups were similar at the start of the trial. This analyses only looks at 155 patients from the 'completer sample', (who received at least 12 sessions and 15 weeks of treatment). Disregarding non-completers may have introduced bias.

i. Meyer B, Pilkonis PA, Krupnick JL, Egan MK, Simmens SJ, Sotsky SM. Treatment expectancies, patient alliance, and outcome: further analyses from the National Institute of Mental Health Treatment of Depression Collaborative Research Program. *Journal of Consulting Clinical Psychology* 2002; **70**: 1051-1055

(Type II evidence - further analysis of an American randomised controlled trial from the National Institute of Mental Health Treatment of Depression Collaborative Research Programme involving 239 outpatients with major depressive disorder (aged 21-60 yrs). Patients were assigned to 1 of 4 treatments: Interpersonal therapy, cognitive-behavioural therapy, impipramine plus clinical management, or placebo plus clinical management.)

2.5d There were almost no differences in either baseline characteristics, outcomes or relationship variables between clients who received services from a **consumer case manager** and clients who received services from a **nonconsumser case manager** across follow-up interviews conducted over a 12-month period. Given this, the present study shows, using a large sample, the ability of consumers to provide mental health services as members of a case management team. Although there were significant effects of Time for almost every outcome measure (clients improved over time), there were no significant Time x Case Manager Type interactions. Staff age, race, or gender did not significantly alter the pattern of these results.[i]

i. Chinman MJ, Rosenheck R, Lam JA, Davidson L. Comparing consumer and nonconsumer provided case management services for homeless persons with serious mental illness. *Journal of Nervous & Mental Disease* 2000; **188(7)**: 446-53

(Type II evidence – secondary analysis of data collected from 2935 homeless participants with serious mental illness participating in the first 2 years of a randomised controlled evaluation of 2 different service conditions in the US (mean age 38.39 years; non-consumer sites n=1985, consumer sites n=950). Structured follow-up interviews were completed at 12 months.)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

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National Service Framework: key action 8

Raising the standard. Cardiff: Welsh Assembly Government, October 2005

Carers have a statutory right to their own assessment and if assessed as eligible for support, a written care plan. The special needs of young carers must be taken into account. [Key action 8 paragraph 14.1]

What are effective interventions for supporting carers?

What are the special needs of young carers that need to be taken into account and how can these needs best be satisfied?

See also Section 7.18 for young carers.

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2.6 Support for caregivers

2.6a There is still uncertainty about the most effective **interventions for carers**. Meeting **'needs'** may not improve **caregiver distress.** Despite concerted attempts to engage carers, only 42% participated in the study. The carers' programme did not offer any significant advantage on any of the outcome measures: psychological morbidity, negative appraisal, coping or social support. The severity of caregiving difficulties decreased over the study period for the group as a whole.[i]

Caveat: Only 61 (40%) out of the 146 carers approached, agreed to participate. 49 carers remained at follow-up.

i. Szmukler G, Kuipers E, Joyce J, et al. An exploratory randomised controlled trial of a support programme for carers of patients with a psychosis. *Social Psychiatry Psychiatric Epidemiology* 2003; **38**: 411-418

(Type II evidence - randomised controlled trial of 61 carers from Camberwell (mean age 54, 82% female), allocated to the intervention or standard care. Due to poor uptake 16 more carers were recruited from Peckham. The results for the Camberwell group are presented, with brief reference to the total group (n=77). Carers were followed up at 6-months post-intervention.)

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2.6b Findings provide some support for an interactive, stress-coping model of caregiving in psychosis. **Effective coping in caregivers** may improve with **support from confidants**. Carer distress may not change while caregiving. Results at baseline were consistent with a stress-coping model. Carer distress was most strongly associated with coping. In turn, coping was associated with 2 sets of factors - 1 related to appraisal and caregiving difficulty, the other to social support. Using a small sample of longitudinal data (n = 38), most individual measures were predictable from baseline. However, there was again a strong association between carer distress and current coping. Support from confidants assumed an important relationship to effective coping. The level of effective coping increased over time while caregiving difficulty decreased, but carer appraisal and distress did not change.[i]

Caveat: The results of this study is limited as an intention to treat analysis has not been performed and so the follow-up model is based on a small subset where there were complete data for every measure (n=38).[i]

i. Joyce J, Leese M, Kuipers E, Szmukler G, Harris T, Staples E. Evaluating a model of caregiving for people with psychosis. *Social Psychiatry and Psychiatric Epidemiology* 2003; **38**: 189-195

(Type II evidence - post-hoc analyses of follow-up interview data available from a UK randomised controlled clinical trial of a support package offered to 77 carers in contact with a community psychiatric service.)

2.6c **Family intervention** directed at **carers' needs** within a standard mental health service can produce benefits for patients beyond the term of intervention. Analysis was carried out on an intention-to-treat basis. There was a significant advantage for family intervention, in terms of relapse (37% relapsed compared to 72%, NNT=3) and on other clinical measures. Treatment group and medication compliance were significant and independent predictors of relapse. There was a significant reduction in carer needs in the intervention group.[i]

Caveat: 22 carers did not attend the full intervention, and only 56 pairs (70.8%) completed the 12 month follow-up. An intention to treat analyses is not reported.

i. Sellwood W, Barrowclough C, Tarrier N, Quinn J, Mainwaring J, Lewis S. Needs-based cognitive-behavioural family intervention for carers of patients suffering from schizophrenia: 12-month follow-up. *Acta Psychiatrica Scandinavica* 2001; **104**: 346-355

(Type II evidence – 12-month follow-up data of a randomised controlled trial involving 79 unselected patient-carer pairs in Manchester allocated to the needs-based cognitive-behavioural family intervention or control group. Main patient outcomes were relapse and symptom severity. Main carer outcomes measured caregiver burden and carers' needs.)

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2.6d The findings suggest that direct **family support** may help people with **dual disorders** to reduce or eliminate their **substance use**. Family economic support was associated with substance abuse recovery in bivariate and regression analyses. Results showed that higher average family expenses on behalf of the study participant were associated with reductions in substance use (p=0.003). Caregiving hours were significantly associated with substance use reduction but not with cumulative substance use (p=0.03). Informal support was not associated with changes in psychiatric symptoms. Further research is needed to confirm this connection and to establish the mechanisms by which support is useful.[i]

Caveat: Due to the longitudinal design of the study, data were collected at different time periods. The number of family interviews completed at each time period varied. Missing caregiver data may have affected the outcomes of the study.

i. Clark RE. Family support and substance use outcomes for persons with mental illness and substance use disorders. *Schizophrenia Bulletin* 2001; **27**: 93-101

(Type II evidence – secondary data analysis from a 3 year randomised controlled trial of 203 people with dual disorder (average age = 34, 74% male) that compared integrated mental health substance abuse treatment within an assertive community treatment approach to standard case management. Caregivers for 174 of the 203 participants were interviewed at least once at 6-month intervals.)