

PRIORITY BRIEFING

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation project.

QUESTION DETAILS

Question ID: 2

Question type: Intervention

Question: Would a parent-delivered programme of training for paediatric ward staff improve the effectiveness of communication with disabled children and their parents when they are admitted to hospital?

Population: Children with disabilities involving difficulties with communication

Intervention: To develop and evaluate an intervention to improve the way in which staff communicate with these children.

Control: The comparison group will receive usual standards of care

Outcome: More effective communication between staff and children and their families. Reduced distress during hospital admission for children and parents. Improved outcomes for children through improved agreement (between parents and staff) of, and adherence to, treatment.

Note:

There is no proven intervention that this question is proposing; therefore this intervention will need to be developed through the collaborative efforts of parents, ward staff and research experts.

Part 1: Research Background

Guidelines: There are no formal guidelines on the communication of staff towards disabled children and their families and no guidelines for the development of interventions (parent-led or otherwise) to improve communications in this area. However, NICE express a commitment to providing opportunities for patients, carers and the public to contribute - alongside health professionals and industry to the collection of evidence that informs guidance.

Research Summary:

No evidence was found that was concerned specifically with parent-delivered training for staff working with disabled children. One systematic review was identified that investigated a similar intervention in another field; involving users in the delivery and evaluation of mental health services. The review found very few studies but concluded that, in general, providers of services who had been trained by users had more positive attitudes towards users but that clients reported feeling less satisfied with services when interviewed by users. This suggests involvement of users in service delivery and evaluation should be considered.¹

No trials could be found investigating the use of parent-delivered programmes to improve communication of staff towards children with disabilities involving difficulties with communication and their parents. There are, however, some related studies involving mental health patients and cancer patients. These studies support the use of some form of communication training for hospital staff to help them work more sensitively with patients and their families. Two studies support the use of service-user led training for staff^{2, 5} while two support intense peer-led training and facilitation^{3, 4}. One review investigating communication skills training for staff working with cancer patients states that “research suggests communication skills do not reliably improve with experience”.³ Those studies on user led training highlight the positive impact on staff attitude towards the patient.

Ongoing Research:

In 2003 on the Cochrane Database of Systematic Reviews a review protocol on ‘Involving service users as trainers for professionals working in adult statutory mental health services’ was published by Simpson et al, based at Health Economics and Decision Science, SchARR, University of Sheffield, but this does not appear to have been completed. The objectives were to find existing evidence regarding any positive or negative effects of user involvement in mental health service delivery as trainers of mental health professionals. Evidence would be sought of the outcomes of involvement for those trained by user-trainers, such as skills developed.

Part 2: Prioritisation Information

1. The health problem

Epidemiology:

In the South West the number of children aged 0-19 years with a long standing illness or disability was 20% in 2000 in comparison with 18% across England. For children with disabling conditions, hospital admissions may be common and so communications between staff and families may be crucial to therapy and the therapeutic relationship. Parents have identified problems with communication as being a major issue for their children during admissions, particularly those who have either a learning disability or specific language or social communication problem.

2. Identification of the topic as a priority:

The Aiming High for Disabled Children (AHDC) programme was launched in May 2007. Its stated aim is 'to improve service provision across the board for disabled children and their families, enhancing equality and opportunity for them'

In the Government's paper 'Valuing People Now' the local South West priority is to focus on relationships with people with learning disabilities but steps to develop this are unclear.

National Service Framework for Children, Young People and Maternity Services highlights the need for training of staff to improve competencies in dealing with children with learning disabilities when they are admitted to hospital and the need for staff to listen to service users and their families to improve their services.

SW SHA Priorities framework 2008-11

- Full implementation of Valuing People: a new strategy for learning disability for the 21st century.
- Fully implement the National Service Framework for Children, Young People and Maternity services.

3. Local perspective

- CIO SPCT (Cornwall and Isles of Scilly Primary Care Trust) priority in reducing the gap in inequalities.

Tractability:

- Strong links to users through Cerebra.
- Feasible? What skills/capacity to develop intervention?
- Would need to develop the intervention before evaluating.
- PenCLAHRC may be a useful influence to encourage receptiveness of services.

- Local expertise/support to enable access exists but provision is variable.

References

(1) Simpson EL. Involving users in the delivery and evaluation of mental health services: systematic review. *BMJ* 2002; 325:1265.

Objectives: To identify evidence from comparative studies on the effects of involving users in the delivery and evaluation of mental health services.

Data sources: English language articles published between January 1966 and October 2001 found by searching electronic databases.

Study selection: Systematic review of randomised controlled trials and other comparative studies of involving users in the delivery or evaluation of mental health services.

Data extraction: Patterns of delivery of services by employees who use or who used to use the service and professional employees and the effects on trainees, research, or clients of mental health services.

Results: Five randomised controlled trials and seven other comparative studies were identified. 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.

Conclusions: 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

(2) Cook, J. A., J. A. Jonikas, et al. (1995). "A randomized evaluation of consumer versus nonconsumer training of state mental health service providers." *Community mental health journal* (3): 229-38.

Preliminary evidence suggests that mental health consumers can successfully serve as peer companions, case management aides, case managers, job coaches, and drop-in center staff. However, few empirical investigations have addressed the use of consumers to train mental health professionals. This project employed a randomized design to test the effects of using consumers as trainers for mental health service providers. Fifty-seven state mental health professionals participated in a two-day training designed to acquaint trainees with the attitudes and knowledge necessary for delivering assertive case management services. Participants were randomly assigned to one of two conditions: one in which they received the second day of training from a consumer and the other involving training by a nonconsumer. Analyses revealed that post-training attitudes were significantly more positive for those participants trained by the consumer. Subjective evaluations also reflected positive reactions to the use of consumers as trainers. Implications for further use of mental health consumers as trainers are explored.

(3) Fellowes, D., S. Wilkinson, et al. (2004). "Communication skills training for health care professionals working with cancer patients, their families and/or carers.[update of Cochrane Database Syst Rev. 2003;(2):CD003751; PMID: 12804489]." Cochrane Database of Systematic Reviews(2): CD003751.

BACKGROUND: Research suggests communication skills do not reliably improve with experience. Considerable effort is dedicated to courses improving communication skills for health professionals. Evaluation of such courses is important to enable evidence-based teaching and practice. **OBJECTIVES:** To assess whether communication skills training is effective in changing health professionals' behaviour in cancer care with regard to communication/interaction with patients. **SEARCH STRATEGY:** We searched CENTRAL (Cochrane Library Issue 3 2001), MEDLINE (1966 to November 2001), EMBASE (1980 to November 2001), PsycInfo (1887 to November 2001), CINAHL (1982 to November 2001), AMED (1985 - October 2001), Dissertation Abstracts International (1861 to March 2002) and EBM Reviews (1991 to March/April 2001). Reference lists of relevant articles were searched. Three further studies were detected in November 2003. **SELECTION CRITERIA:** Randomized controlled trials or controlled before and after studies of communication skills training in cancer health professionals, measuring changes in behaviour/skills using objective and validated scales. **DATA COLLECTION AND ANALYSIS:** Two reviewers independently assessed trials and extracted data. **MAIN RESULTS:** Of 2824 references, 3 trials involving 347 health professionals were included. One provided an intensive 3 day course then assessed oncology doctors interacting with 640 patients; a second provided a modular course then assessed role plays with oncology nurses; the third was modular and assessed outcomes with clinical and simulated interviews and patient questionnaires. In one trial, course attendees used more focused questions (probability < 0.005), focused and open questions ($p = 0.005$), expressions of empathy ($p < 0.005$) and appropriate cue responses ($p < 0.05$) at follow up than non-attendees. No significant differences were found between attendees and non-attendees for leading questions. From baseline to follow up, attendees had significantly different changes in rates of leading questions ($p < 0.05$), focused questions ($p < 0.005$), open questions ($p < 0.05$) and empathy ($p = 0.005$). The only observed significant difference in the second trial was that trained doctors controlled the follow-up interview more than untrained doctors ($p < 0.05$). Neither studies found differences in summarising, interrupting and checking. The third trial found trained nurses used more emotional speech than untrained counterparts, particularly regarding anxiety and distress. Patients interviewed by trained nurses used more emotional terms, but no differences emerged in questionnaires. **REVIEWERS' CONCLUSIONS:** Training programmes assessed by these trials appear to be effective in improving some areas of cancer care professionals communication skills. It is unknown whether this training would be effective if taught by others, nor the comparative efficacy of these programmes.

(4) Gysels, M., A. Richardson, et al. (2005). "Communication training for health professionals who care for patients with cancer: a systematic review of training methods." *Supportive Care in Cancer* **13**(6): 356-66.

BACKGROUND: Effective communication is increasingly recognised as a core clinical skill. Many health and social care professionals, however, do not feel adequately trained in communicating and in handling interpersonal issues that arise in the care of patients with cancer. **AIM:** The aim of this paper was to assess the effectiveness of different training methods used in communication training courses for health professionals. **METHOD:** We searched six computerised databases and augmented this with follow-up of references and grey (unpublished) literature. We included all studies evaluating communication training and assessed methodological quality according to the standard grading system of the Clinical Outcomes Group. Data on author, year, setting, objectives, study design and training methods were extracted and compared in tabular format. **RESULTS:** A total of 47 studies potentially assessing communication training were identified. Sixteen papers were included evaluating 13 interventions. Four were randomised controlled trials (RCTs) (grade a); the others were grade III. Eleven interventions trained health professionals; two trained medical students. Interventions for training in communication skills were characterised by the variety of communication approaches used and a diversity of methods. They were applied to health professionals with very different roles, served different purposes and evaluated a variety of outcome measures: behavioural assessments, patient outcomes and professionals' self-report. **CONCLUSIONS:** The best results are to be expected from a training programme that is carried out over a longer period of time. Learner-centred programmes using several methods combining a didactic component focusing on theoretical knowledge with practical rehearsal and constructive feedback from peers and skilled facilitators proved to be very effective. Small groups encouraged more intensive participation. Training in communication for both medical or nursing students and senior health professionals is advisable. [References: 34] cut this!

(5) Wood, A. L. and O. F. Wahl (2006). "Evaluating the effectiveness of a consumer-provided mental health recovery education presentation." SO: *Psychiatric rehabilitation journal*(1): 46-53.

The current study investigated the effectiveness of the In Our Own Voice (IOOV) mental health education program in improving knowledge and attitudes about mental illnesses. Undergraduate participants (N = 114) completed three pre-test measures of knowledge and attitudes, attended either an In Our Own Voice presentation or a control presentation about psychology careers, and repeated the three measures following the presentation. Results indicated that the IOOV group showed significant positive change across time, as well as significantly greater improvement than a control group in their knowledge and attitude scores on all measures. These findings support the effectiveness of the IOOV program.