

# **“Dementia Focus”**

## **Developing a Local Centre for Expertise in Dementia**

**Minutes of the Executive Committee held at UEA, Norwich  
on Monday 13<sup>th</sup> June 2005**

### **Present:**

Dyllis Faife (Chair)	Norfolk Social Services Department (Operations Manager)
Ann McDonald	UEA (School of Social Work and Psychosocial Studies)
Becky Heath (Minutes)	UEA (School of Social Work and Psychosocial Studies)
Emily Millington Smith	Alzheimer’s Society
Dr. Tom Dening	Fulbourn Hospital, Cambridge (Consultant Psychiatrist)
Dr. Charles Morris	Julian Hospital, Norwich (Consultant Psychiatrist)
Gordon Slack	Age Concern Younger Person with Dementia ACCESS team
Sarah Linsell	Cambridgeshire Social Services
Prof Amanda Howe(attended for final ½ hour)	UEA (School of Medicine)

### **Apologies** were received from:

John Hawkins	Service Manager (OPMH) Cambridge Locality
Moira Clare	Suffolk Social Care Services

### **Agenda Items**

1. Minutes and Matters Arising
2. Alone with Dementia Feedback
3. Dementia Care Mapping Feedback
4. Northern Dementia Service Collaborative
5. Membership of Executive Dementia
6. Discussion with Prof Amanda Howe about links with Med at UEA
7. AOB

### **1. Minutes and Matters Arising**

The minutes of the last meeting were read and checked for accuracy.

### **2. Alone with Dementia Feedback**

BH and AMcD went through the Interim Report (attached) which was submitted to the Dept of Health at the end of April and reported that no feedback had been received from the funders. Issues arising:

- Identified gap in knowledge is how to effectively incorporate the views people with dementia in the research. The current research is of too short a time frame to tackle this but it was considered to be a suitable subject of a future grant application. The literature review has revealed that research carried out to date is of a high standard but limited and there is a great deal more to be learnt on this subject.
- There is a striking lack of research that has been carried out which combines mental health and rurality – mainly general policy documents re: rurality and social inclusion.

Discussion:

- More detail was given by BH re: the Talking Mats method of carrying out interviews with people with communication difficulties. This method is currently being used by researchers in AHP at UEA to interview people with learning difficulties and could be adapted for use with people with dementia. A workshop on the method is due to be held at UEA in the

autumn – BH to provide details nearer the time. EMS suggested piloting the method over the remaining few months of the Alone with Dementia project. Discussion was had around the difficulties of obtaining ethics approval and the need for any research proposal that involved people with dementia to be extremely rigorous and well researched and planned in order to safe guard participant's wellbeing. There was some discussion around the possibility of the Alzheimer's Society being able to provide funding for further research – DF and EMS to discuss.

- Some discussion was had around the issues of providing care to people from traveller communities.
- TD pointed out that the original proposal was for the research to identify the need for an intervention of some kind. There is scope for interviewing people with dementia as a further research study and this has enough novelty to be useful. A discussion was had around possibilities of further funding. The DoH deadline has now passed for 2005 but it would be a possibility for 2006-2007. DoH are generally keen to build on initial projects though they are not so keen on extensions to existing funding so it would need to be for a new project. AMcD is currently pursuing discussions with AHP at UEA about the possibility of collaborating on a project involving people with dementia. DF mentioned the Balance Foundation and said that people with dementia would fit into their criteria. GS said that their research worker was funded by the Lankelly Trust. Also that the Joseph Rowntree Foundation would be a possibility.
- DF said that Dementia Focus needs to make a decision about whether they would support an application for further funding to extend the study. Also, whether members want to pursue funding to involve people with dementia. TD also posed the question of whether members want to pursue long term or short term funding and/or explore the possibility of funding a Phd. AMcD talked about case studentships in partnership with the voluntary sector. DF suggested the need for an action plan to explore these possibilities. She asked if the group wanted to wait until next year and have a gap from the end August 05 when BH's contract finishes. TD suggested that an application to Research for Aging might tide the research process over for 3 months. AMcD said that a new white paper on adult care was due in the Autumn and that it was likely to be about supporting people to commission their own care. AMcD offered to work with Julia Warner to look at what funding was available. Everyone else agreed to research other opportunities and email round the group if anything came up between now and the next meeting.

### **3. Dementia Care Mapping**

Most places were filled – 88/90. People came from across the 3 counties to each session (benefit: mix of people from agencies and counties / downside: travel times and costs). The majority of people passed the training and feedback was very positive (nurses, care staff, OTs and CSKIE). Judith Farmer will now do a proper analysis of feedback and longer term evaluation of impact: awareness of person centred perspective? is mapping being used in workplaces? has care for people with dementia improved? There is funding available for 50 hours work for JF to carry out a survey/questionnaire and carry out interviews with some staff. DF will ask her to feedback to the senior management group at Social Services to look at training budget and will also go to the Strategic Health authority. EMS feedback that the Alzheimer's Soc place would definitely be followed up. DF said that they had tried to have 2 people from each workplace so that they could support each other to take it forward. Also that a regional group had been set up for trainees to gain mutual support.

CM raised the possibility of further funding for training. DF said that she wasn't sure whether further training should be pursued by Dementia Focus or by the individual agencies represented on it. Also, the possibility of Training for Trainers was discussed. EMS asked about the benefits to people living at home. TC felt that it was for local agencies to follow-up individually and that

Dementia Focus should decide what it wants to push as a group. DF will ask JF to email report and questionnaire draft round the group for feedback on questions.

#### **4. Northern Dementia Service Collaborative**

DF posed the question of whether the group should visit the collaborative and find out more. Also about general thoughts for pursuing this direction. CM had seen a talk about it at the Old Age Faculty AGM in Amsterdam. That the collaborative had developed a very effective mechanism and that it would be best to go and visit to find out more. There was some discussion about the funding issues involved in developing a collaborative and/or whether the Northern Collaborative had a research focus at all. CM/TD felt that specific questions were needed to make a visit more useful. DF suggested waiting until the sept meeting to decide on a question but that she would contact the collaborative now to explore possible dates. TD suggested that the group could offer to share info about YPw/D and Alone with Dementia in exchange for info they could share with the group. DF to ask for dates for possible visit in October 05.

#### **5. Membership of Executive Dementia**

Norfolk – DF, CM, EMS

Camb – TD, JH, SL/JF (shared place)

Suffolk – GS, AD, MC

University – AMcD (UEA)

CSKIE? AMcD and BH to meet with CSKIE and invite lead person to attend the next meeting.

TD to contact Sarah Laughton (P'boro) to discuss membership of group

#### **6. Discussion with Prof Amanda Howe about links with Med at UEA**

DF explained that Dementia focus is looking to develop links with a medical school and enhance links between schools at UEA – Med, Swk, Law and AHP. AH feedback that she had tried to engage colleagues for representation on the group with little success. The issue seems to be that Med is a new school with only small numbers currently coming in and amongst them nobody who specialises in dementia. AH said she had lost track of what Dementia Focus's remit is and has had trouble in identifying how an academic partner would benefit the group. Med's needs are in terms of teaching and research. Students benefit from placements as well as campus teaching and Med is looking for partners to contribute to both. DF is already involved in this. Within the school's research remit, psychological health is one of the main themes and screening for dementia in the elderly is one of AH's research interests. There is a difficulty of how to interest people in the group when dementia isn't their research interest. There are 2 posts coming up in the autumn and AH suggested mentioning Dementia Focus as something that the new post holders could take on if it coincided with their areas.

DF feedback that within SWK, the fact that dementia focus exists and is hosted there has meant that dementia has developed as a focus within the school. UEA brings neutrality from statutory bodies and the intention is to encourage and grow something around dementia as a speciality focused on UEA – this helps recruitment for services across the area. It would be useful to have Med's academic perspective as well as Swk's.

TD feedback that the structure of the group was such that the group could be opportunistic and flexible. The group is interested in training, research, information and service development. Its major strength is its representation across the 3 counties. UEA isn't the sole academic partner but it is key particularly with the involvement of Swk in the research project: Alone with Dementia in Rural areas. Another possibility is a relationship with the Institute of Health rather than Med in particular. DF and AMcD gave more details about the successes of the last year: DCM and Alone with Dementia in Rural Areas and also the possibilities of future research projects and possible

collaboration with AHP re: involving people with dementia. EMS said that it was useful to have a group of people who had connections outwith the group and “hands on the ground”.

AH mentioned that people tend to attend groups if its about pursuing their own interests/service development – this may be a barrier to attending Dementia Focus. DF said that the group was about linking the strategic and the operational with research at UEA that can be used to benefit service users and carers. AH felt that now was the time to identify someone from the Inst of Health – that they don’t necessarily have to be a researcher but someone with an interest. AMcD said that Dementia Focus had been key locally in developing a research/practitioner focus. This fits in with the teaching agenda and continuing professional development agenda.

AH said that she would ask the new posts to link in depending on their background. She would also talk to the Inst of Health psychology and psychiatry stream to see if there are any possible links. She will give name of link person to AMcD as well. Primary Care MH research is a focus so AH would be delighted to be approached re specific research collaborations.

## **7. AOB**

NIHME – 11<sup>th</sup> October – annual conference at Newmarket

### **Date for next meeting:**

5<sup>th</sup> September 2005, 10am – 12 noon at UEA