IN OUR SHOES: A USER AND CARER LED TEACHING MODULE

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on behalf of the In our Shoes Steering Group

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Foreword

I was originally lured into teaching, very sneakily I might add, by Dr Benbow, who put it to me as a "talk" to students, so here I am talking to you about my experience on the modules, we have all been taking part in.

For me my teaching on the module was very rewarding, as I felt the module was a moving forward into making a difference. It supports my theory and drum beating that all departments of the system need to come together, communicate their findings to each other. On this module I feel that this has happened; as proof, we are all here, passing on what we have learnt, teaching each other.

In my teaching I hope I have been a voice for the needs and position of users in the system and community. The teaching is, and was, a two way thing; I myself learnt things about myself and the system. As users teaching gives a prime opportunity to show the true realism of mental deterioration and the complex problem of finding a care system that will work for all. The module gave me that chance: for who better to teach than those who live it and those who live with it, first hand teaching, knowledge to be passed on. Teaching how it is when people you have known all our life, treat you as if you are already dead, teaching when you remember the far past but not the past of yesterday, valuable teaching.

To my mind teaching is a sharing of knowledge and information and this module has enabled us to come together to pool our different and unique fields of knowledge, to make that better system of care we all aspire to. I was able to bring my voice and views in the hope of teaching where I felt changes needed to be made, teach the practical side of mental disturbance, to marry it with theory. I see us as segments of an orange, no shape or form, unless we hold together; teaching gives us that, learning gives us freedom.

People say "why bother, nothing will change", but it can and will. We have to believe that, working together, users, carers, and professionals teaching one another, surely, surely **will** make a difference.

Kath Morgan

Note: Kath presented these thoughts in a talk at the workshop entitled Piecing together the jigsaw: sharing experiences of involving users & carers in education at Staffordshire University on April 25th 2008 when teams from Staffordshire, Wrexham, Leicester and Nottingham came together to share their experiences.

Foreword

It was always difficult to conceive how a carer might portray experiences to an audience with the capacity to effect change but "In our shoes" seemed to present this possibility. Being a carer is a shock to the system (and that probably includes or will include most of us!) but few perhaps have the opportunity to reflect in a really positive way. The conception of this course was not stereotyped but came as the result of brainstorming, adjusting and readjusting sights, and the realisation (for me) that experiential learning could and should be the backbone of a course which had the capacity to change the attitudes of professional practitioners. More questions than answers would inevitably be raised but this was a strength of a course designed to make participants think and consider their position in relation to the enormous and growing problem of ageing and mental health. Personally it was a privilege to think that my own experience and reflection might in some small way enable others to benefit. Despite some reservations, meeting the students was positive and reassuring because they had a genuine concern to listen. This course is a small but unique start to effect change which could touch the lives of many thousands of, as yet, unsuspecting people.

Graham Hughes

Background

Several important strands form the context of this project:
- policy context
- personal context
- university context

The policy context

A shift in the balance of power in health services towards the service user was initiated by the NHS Plan (Department of Health, 2000). The Plan aimed to increase both user involvement and public participation in all aspects of health care:

> *For the first time patients will have a real say in the NHS. They will have new powers and more influence over the way the NHS works.*
> (page 12).

This shift has continued over recent years: health and social care has been moving towards greater patient choice, greater patient influence in services at all levels, and more personalised health and social care (Department of Health, 2005a; Department of Health, 2005b) alongside stronger public involvement (Department of Health, 1999; Department of Health 2002; Department of Health, 2006). Person-centred care is included as standard 2 in the National Service Framework (NSF) for Older People (Department of Health, 2001), and carer support is one of the standards in the NSF for Mental Health (Appleby, 2004). One of the challenges of this policy imperative is how to change organisational culture in order that users, carers and the public can have a voice and influence services. The House of Commons Health Committee (2007) highlights two important points:

> *Structures and procedures ..... will have little effect if the health service is not prepared to listen and make changes as a result of what they learn.*

and furthermore

> *Effective patient and public involvement is about changing outcomes, about the NHS and social care providers putting patients and the public at the heart of what they do.*
> (page 5)

Skills and training have been identified as key issues in developing the involvement of patients and the public (Picken et al, 2002). However, if learning from, and working with, users, carers and the public is seen solely as a policy imperative it is unlikely to become embedded in future practice. Rose et al (2002) put this clearly:

> *There is a danger that government demands for agencies to demonstrate user involvement may mean that user activities become a formal procedure to be ticked off, rather than an embedded and powerful organisational practice.*
> (page 16-17)

Involvement is more likely to succeed if health and social care professionals at all levels are able to experience the benefits that follow from developing partnership with both those who use their services and those who might.

Does education offer a way of influencing the system? It can be argued that the involvement of users and carers in education at all levels is essential if health and social

care services are to develop partnership working with people using their services in line with these recent policy initiatives, and Tew, Gell & Foster (2004) describe how this may involve users and carers in a range of activities, including:

- direct delivery of learning and teaching
- course / module planning
- programme management
- recruitment & selection of students
- practice learning
- student assessment
- course evaluation
- joining courses as participants

Involving users and carers at all levels of education sends a powerful message to the professionals they train about the value and importance of hearing and attending to the voices of those using their services.

The personal context

Katz and colleagues (2000) described the development of a Council of Elders:

> *an educational innovation in which we invited community elders to function as our 'Senior Faculty', to whom medical residents present their challenging and heartfelt dilemmas in caring for elder patients. In the conversations that ensue, the elders come to function not simply as teachers, but collaborators in a process in which doctors, researchers, and elders together create a community of resources, capable of identifying novel ways to overcome health-related difficulties which might not have been apparent to either group separately.*

They argue that this model not only allowed the elders to provide good advice on dilemmas presented to them, but to provide 'life world and value orientation' which helps the professionals involved to appreciate better the experience of older adults and what matters most to them. They also noted how it addresses ageism and stigma. This work was presented at a powerful workshop[1] in 2003 by Arlene Katz and Glenda Fredman.

Some national work at the Royal College of Psychiatrists also influenced thinking about this project. The Royal College of Psychiatrists and the Princess Royal Trust for Carers ran a campaign called Partners in Care between 2004 and 2005. It aimed to draw attention to the problems faced by carers of people with mental health problems and to encourage partnership between carers, users and the professionals working with them: it also aimed to change attitudes (Shooter, 2004). The Campaign encouraged the Faculty of Old Age Psychiatry to pursue the involvement of users and carers in its work in collaboration with the Alzheimer's Society and Age Concern, and led to the development of a Consumer Group, which was perceived to have a powerful and creative influence on the work of the Faculty itself (Ong et al, 2007). As part of the Consumer Group's work, carers, who wished to share their experiences, prepared narratives for the Group and the narratives themselves provided the impetus and inspiration for further partnership work (Benbow et al, 2008).

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[1] Workshop title: Collaborative Conversations: Reflections on our Practices, at the meeting entitled A space for age and a place for families: a systemic focus in older adult services

The university context

The involvement of users and carers in teaching (and in health and social care generally) is an area of growing interest. Lloyd, Carson & Bleakley (2007) recently reported on a project which investigated the needs of service users involved in planning and delivering mental health services and education: they also produced a toolkit for developing the role of users and carers in education, planning and research. Similarly, Anderson, Ford and Thorpe (2008) have described interesting work with people with communication needs. The Centre of Excellence in Interdisciplinary Mental Health at the University of Birmingham and Suresearch (http://www.ceimh.bham.ac.uk/centre/CarerInvolve.shtml and http://www.suresearch.org.uk/index.html) support user and carer involvement in research and education and some useful resources are available on their websites. Other resources are available through the Centre for Excellence in Healthcare Professional Education (see http://www.cetl4healthne.ac.uk/CETLPlone/strands/2018people-with-experience2019-2013-user-involvement).

Staffordshire University offers a Master of Science in Applied Studies in Ageing and Mental Health. Students on the course come from a wide range of professional backgrounds, including occupational therapy, medicine, mental health nursing, residential/ nursing homes, and are normally working in a setting with older adults who have mental health problems during the course. During the academic year 2005-2006 as part of the MSc module in assessment and care planning, a user was asked to teach one session and two carers taught sessions. The aim of involving them was to give students a different experience of assessment and care planning, and to bring into the classroom the experiences of users and families involved in assessment and care planning in older people's mental health services and similar settings. The user session attained the highest score of all module sessions on the three aspects rated by students in their feedback, namely information, interest and enjoyment (Benbow, Taylor & Morgan, 2008).

Module evaluation by the student group provoked debate and reflection about the 'added value' of the user-led session. Teaching staff hypothesised that the session 'brought to life' the experience of going through an assessment and care-planning process in a way that can only be done by those who have had that experience.

Subsequent meetings led to a proposal to develop a new module designed and run by users and carers for future inclusion on the MSc course. A group put together a proposal to the HEA for funding for a mini-project with the following aims:

- To establish a curriculum group to write a module on user and carer experience in older people's mental health for MSc students
- To establish and train users and carers to teach and assess on the module
- To run the module starting September 2007
- To evaluate the module and revise as necessary
- To disseminate the findings
- To consider how to generalise the module/ learning to other courses

The outcomes expected were as follows:

- Module guide
- Final Report
- Publications in professional journals
- Presentations to conferences/ learned societies

Preparation of the Module

Establishing the steering group

The first stage of the Project was to establish a Steering Group which met throughout. Members of the Steering Group are listed in Appendix 1 and included:

- Staff of the Centre for Ageing and Mental Health
- A contact from Users in Partnership
- A carer who had made contact with the Centre
- A contact from the Alzheimer's Society
- A user who had taught on the MSc previously
- The Chief Officer of a local voluntary organisation

Members of the group discussed how to develop the curriculum and identified the following aims for the module:

By the end of the module students should

1. understand some of what it is like to live with a mental health problem in later life
2. understand some of what it is like to be a carer of an older adult with a mental health problem in late life
3. have re-evaluated the relationship between health and social care professionals and the users and carers they work with
4. have re-evaluated what health and social care professionals have to offer in their relationship with users and carers.
5. have experienced learning from the people they work with in their professional capacity

The Steering Group agreed on the following assignment:

An ASSIGNMENT length 3500 WORDS weighted at 100%.

Written paper of 3500 words reflecting on an innovation in practice with users and carers.

Developing the Teaching Plan using Focus Groups

The Steering Group arranged to set up focus groups with users and carers to explore with them what they would like professional staff to learn on the course. Three focus groups

were organised one with carers, one with users, and one with users and carers together, using links from the steering group.

The focus groups addressed the following areas: the aims of the module, what service users and carers would wish to teach professionals, what challenges they would anticipate and what training might be needed. Focus group participants agreed to the group discussions being tape-recorded. The tapes were transcribed and analysed by a member of university staff not involved in the project. Her detailed thematic analysis was then fed back to the steering group who identified major themes around which they designed the teaching plan (paper in preparation). The final teaching plan is set out in Appendix 2. The design of the teaching plan includes the requirement for the students to interview users, carers or families (with their consent) on various topics at regular intervals during the course, and then briefly present their learning during teaching sessions. This feature of the course grew from the work of Katz et al (2000).

The Resource List

During the initial preparation period a Resource List was developed. This did not aim to be comprehensive but instead to offer suggestions of items to stimulate reflection and learning in various areas. The students were recommended to read a broad range of literature, including fiction and non-fiction, poems and plays, as well as reflecting on works of art and other sources. The Module Resource List (as at January 2008) is available on the In our Shoes website but is a document in evolution.

Recruiting users and carers to teach

In late June 2007 a recruitment workshop for users and carers who might be interested to be involved in teaching took place at the university. It was advertised through steering group contacts as follows:

> We are looking for individuals who would be interested in finding out more about teaching on the above module. The workshop will cover the delivery format of the module; what will be involved, travelling costs and how to sign up.

The workshop was attended by nine users and carers. It ran for two hours and covered the following areas:

- Introduction to the university and to the people involved in the course
- Practical aspects of teaching
- Different ways of teaching and support on offer
- What is it like to teach?
  - o This talk was given by a user who had previously taught at the University on the assessment and care planning module. A podcast of the talk is available on the In our Shoes website.

Challenges in the early stages

An interim report on the project (available on the In our Shoes website) was produced in July 2007 and identified several challenges in the early stages of the project which have continued throughout the course of the project:
:
● Maintaining engagement

The main initial challenge involved consolidating the engagement of the organisations which were involved at the start of the project but whose circumstances fluctuated over time. Users in Partnership was heavily involved initially but changes in the organisation and funding of the National Institute for Mental Health England led to uncertainty regarding its future. North Staffordshire Pensioners Convention was involved in the initial stages of planning the project and also contributed a teaching session. The Alzheimers Society and Approach (a mental health organisation based in Staffordshire) came on board at a later stage and were enthusiastic in organising the focus groups to develop the teaching plan. The Alzheimer's Society introduced the Phoenix Centre which hosted focus groups. A lot of work was expended in keeping up and building on these links and liaising with the individuals involved.

● Supporting user and carer teachers.

Potential user and carer teachers were invited to the recruitment workshop at the university. Some committed to involvement at that stage and the module co-leaders have supported them throughout the preparatory, delivery and feedback phases. The time expended on this has been regarded as important to the success of the project but should not be under-estimated. The support of other Centre for Ageing and Mental Health staff has also been important: the Centre Administrator achieved honourable mentions in feedback and other Centre staff have gone out of their way to welcome and engage with the visiting users and carers.

● Maintaining the focus of teaching.

Much of the preparation work involves focussing on the learning objectives set for the teaching sessions and how they will be met. The preparation involved is considerable.

A further challenge for the team was a last minute change in timescale. The original plan was that the module was due to run for the first time starting in September 2007 and finishing in December 2007, but it was deferred at short notice to start in January 2008. The delay had one advantage: it allowed time for revision so that the Module became a core module on the MSc rather than an option (as previously planned) so in future all students undertaking the MSc in Applied Studies in Ageing and Mental Health will be required to undertake the module.

Module delivery

The module was delivered over 13 weeks from January to April 2008. The teaching plan is set out in Appendix 2. The original plan was to involve a user or carer or both each week with one module co-leader working alongside them, firstly to prepare the session and secondly to deliver it. Inevitably there were weeks when last minute problems necessitated a change of plan, so some weeks a video of a user, carer or similar was used in teaching. Table 1 shows the people involved and use of videos for 11 weeks of teaching in the classroom. One week was allocated as a reading week and the final session was devoted to feedback and review of the module.

Module evaluation plan

Evaluation was built in throughout module delivery. Students were asked to complete feedback forms after each teaching session (Appendix 3 sets out the Student Feedback Form) and users, carers and others were sent feedback forms with a letter thanking them for their involvement (Appendix 4 sets out the User/ Carer Feedback Forms). These latter forms could be returned by post (stamped addressed envelope was supplied) or provided by email or completed over the telephone if preferred (one person opted for telephone completion).

In addition during the final session a focus group was conducted with students to get their ideas about the added value of involving users and carers in teaching, whether the module had achieved its intended aims, ideas about future changes to the module and their views about the use of videos.

A focus group arranged with users and carers who had been involved in teaching took place at Approach in Stoke-on- Trent in order to get more detailed feedback from user and carer teachers about their experience on the module (publication in preparation).

Discussion of module evaluation

Student evaluation

The students evaluated the Module positively and made many helpful comments. They felt that the weeks when videos were used could not be expected to have the same impact as when users and carers were present in the classroom as the possibility for dialogue with users and carers was lost. They made a number of suggestions of how to improve the course in future.

The student focus group feedback included some practical suggestions, including
- Could use a webcam for people who are too anxious to speak in front of others
- The module could be made into a roadshow to access a wider group
- It might be helpful sometimes to include users, carers and the professionals from both health and social care who have worked with them to get their perspectives
- It might be powerful to 'follow a person' through different parts of their journey
- Another possibility would be to ask a family to talk from their differing perspectives and to track their experiences

Teacher evaluation

All the invited teachers felt that their sessions had gone well, that they had been supported and put at ease at the University, and that the students had been respectful and interested. All but one reported that they had enjoyed themselves: one reported feeling under pressure to perform:
> *I felt it was about achievement rather than enjoyment*

All reported that they would consider teaching again. One person had seen their involvement as a one-off and one person didn't answer this question.

The main area identified for attention was the question of payment and expenses. In setting up the Module the team had believed that users and carers would be paid lecturer fees and travelling expenses, but the University had tightened its procedures before the Module started and had limited access to lecturer payments. This caused confusion and lack of clarity. It is an area which has been brought to the University's attention as needing to be resolved before the Module runs again.

The teachers focus group feedback highlighted some practical suggestions:
- Asking the students to pose questions to users and/or carers in advance of session
- From two couples came the suggestion of perhaps giving carers time to talk on their own with the student group and the users separate time to talk with the students
- Preparing useful teaching tips for users and carers
- Perhaps also preparing some tips for professionals who are involving users and carers in teaching eg don't call it teaching!
- Offering people the opportunity to observe sessions before they go and teach

Co-leaders reflections

The role of co-leader was stimulating because, despite much preparation, it was difficult to predict how the teaching sessions would go on the day, so the co-leader needed to be prepared to improvise and be highly flexible. Liaising with and supporting the teachers who came in to the university demanded a great deal of time over the course of preparing for and delivering the Module. It was useful to have some videos in case the invited speaker was unable to come at short notice but tailor-made videos are probably better teaching aids than others, as they focus on the topic and learning objectives for the session.

By including interviews with users and carers and feedback from them throughout the module, the teaching team aimed to give students the opportunity to have new and different conversations with the people they work with. In evaluating the module it is not possible to investigate whether the students will practice differently in future, but this is an area which could usefully be investigated in future. One of the stated module aims was that students should:

> "have re-evaluated the relationship between health and social care professionals and the users and carers they work with".

A big challenge for the future is to work to understand how we can help people to work differently within the constraints of the health and social care system. This project is a small step towards understanding how to do this.

One issue raised in discussion has been the 'generalisability' of experience described by users and carers (Schofield, 2007). Inevitably, in starting to involve users and carers as teachers, the individuals who take this on will be special people, who could be described as 'trailblazers', people with the confidence, energy and communication skills to take on a

challenge whilst coping with an illness themselves or caring for someone who is. Offering a variety of different ways to be involved may enable a wider range of people to consider involvement and developing the teaching team's confidence and skill in supporting users and carers and working alongside them is also important. The teaching team came to the view that the individual material brought by users and carers, whilst clearly important and influential, is only part of the learning experience and the process of the sessions is equally powerful, ie learning from users and carers, having the opportunity to talk, question and debate with them in an educational environment.

McNamee (2007) has written about teaching as conversation. During module delivery users and carers brought their experiences and aspirations to life in the classroom, and allowed the co-leaders and students to share them in conversation. All concerned testified to the impact this had during the evaluation process.

The very nature of experiential learning raises many questions and has the ability to challenge working practice. Most of the students had many years experience of working in health and social care settings, supporting older people with mental health issues and their families. This wealth of knowledge was juxtaposed in discussion against the experiences and accounts of those using health and social care services. This coming together of health/social care professional and patient/service user/ carer in a common purpose of greater understanding and knowledge of individual needs demonstrates that people's experience of services has tremendous power when delivered in a face-to-face environment. It acts as a catalyst to change a 'one size fits all' approach, to a measured and considered individually tailored (handmade shoe) model of social and health care provision. To facilitate, and sometimes empower, people that use services is a humbling experience for all participants who embrace a person centred approach to health and social care practice. For users and carers teaching has a part to play in this.

Conclusions

The project has achieved the aims set out at the outset:
- A curriculum group was established and developed a module on user and carer experience in older people's mental health for MSc students. Users and carers were involved in curriculum design and throughout the delivery of the teaching.
- The team established links with users and carers, and offered them support and training to enable them to teach and assess on the module. The project demonstrated that users and carers who have traditionally been regarded as hard to involve can make a powerful contribution to the design and delivery of teaching, with support and commitment from their colleagues in education.
- The module was successfully delivered in early 2008
- A detailed evaluation was conducted and demonstrated the powerful impact of the course on students.
- The findings have already been shared in a variety of different settings and further presentations and publications are anticipated.

The final aim:
- To consider how to generalise the module/ learning to other courses

This is currently under discussion, alongside an exploration of how to implement an equitable system for paying expenses and fees to users and carers who teach on future modules.

The project provides a 'case example' of the involvement of users and carers in postgraduate teaching which may be useful for teachers of other higher educational courses who wish to involve users and carers in their study programmes.

The main action for the team to take forward is to further this work and to encourage those within the University and in a range of other clinical and educational contexts to take up the challenge of working with users and carers to better train the health and social care professionals of the future. The team aims equally to inform users and carers involved in older people's mental health services of how powerful and unique their contribution can be, and to encourage them to become involved in teaching. In Kath's words:

> *"users, carers, and professionals teaching one another, surely, surely will make a difference".*

Table 1: Involvement of users, carers, others and videos in module delivery

Persons involved	Number of sessions
Users only	2
Carers only	2
Users and carers jointly	2
Community group	1
Specially made video with user	1
Teaching video of family	1
Commercially made video	2

References

Anderson ES, Ford JS & Thorpe LN (2008) Listening to users and carers who have limited communication capacity or skills. Report to the HEA. Download at: http://www.health.heacademy.ac.uk/publications/miniproject/2008anderson.pdf (Accessed 26/9/08).

Appleby L (2004) The National Service Framework for Mental Health – five years on. Department of Health: London. Download at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4099120 (accessed 26/9/08).

Benbow SM, Ong YL, Black S, Garner J (2008) Narratives in a user and carers' group: meanings and impact. International Psychogeriatrics, in press.

Benbow SM, Taylor L & Morgan K (2008) Multiple perspectives: Involving users and carers in educating health and social care professionals. Quality in Ageing (2008) 9(2): 12-17.

Department of Health (1999). Patient and Public Involvement in the New NHS. NHS Executive: Leeds. Download at: http://www.dh.gov.uk/en/PublicationsAndStatistics/LettersAndCirculars/HealthServiceCirculars/DH_4004176 (accessed 26/9/08).

Department of Health (2000) The NHS Plan: A plan for investment. A plan for reform. Department of Health: London. Download at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_4002960 (accessed 26/9/08).

Department of Health (2001) National Service Framework for Older People. Department of Health: London. Download at: http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_4003066 (accessed 26/9/08).

Department of Health (2002). Shifting the Balance of Power: The Next Steps. The Stationery Office: London. Download at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008424 (accessed 26/9/08).

Department of Health (2005a) Creating a patient-led NHS: delivering the NHS improvement plan. Department of Health: London. Download at: http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4106506 (accessed 26/9/08).

Department of Health (2005b) Independence, well-being and choice: our vision for the future of social care for adults in England. Department of health: London. Download at: http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4106477 (accessed 26/9/08).

Department of Health (2006). A stronger local voice: A framework for creating a stronger local voice in the development of health and social care services. Department of Health: London**.** Download at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4137040 (accessed 26/9/08).

House of Commons Health Committee (2007). Patient and public involvement in the NHS: Third report of sessions 2006-7 Vol 1. HMSO: London. Download at: http://www.publications.parliament.uk/pa/cm200607/cmselect/cmhealth/278/278i.pdf (accessed 26/9/08).

Katz AM, Conant L, Inui TS, Baron D & Bor D (2000) A council of elders: creating a multi-voiced dialogue in a community of care. Social Science and Medicine, 50: 851-860.

Lloyd M, Carson A & Bleakley C (2007) Exploring the needs of service users involved in planning and delivering mental health services and education. Report to the HEA. Download at: http://www.health.heacademy.ac.uk/projects/miniprojects/mlloyd_reportsummary (Accessed 26/9/08).

McNamee S. (2007) Relational practices in education: teaching as conversation. In: H. Anderson & D. Gehart (Eds) Collaborative therapy. Relationships and conversations that make a difference. Pp 313-335. Routledge: London.

Ong YL, Benbow SM, Black S, Garner J (2007) A Consumer Group: Reflections on experience of involving users and carers in the work of the Faculty of Old Age Psychiatry. Quality in Ageing 8: 45-49.

Shooter M (2004) Partners in care? Psychiatric Bulletin, 28: 313-314.

Picken C, Popay J, Staley K, Bruce N, Jones C & Gowman N (2002). Developing a model to enhance the capacity of statutory organisations to engage with lay communities. Journal of Health Service Research and Policy 7(1): 34 – 42.

Rose D, Fleischmann P, Tonkiss F, Campbell P & Wykes T. (2002) User and carer involvement in change management in a mental health context: Review of the Literature. Report to the National Coordinating Centre for NHS Delivery and Organisation R&D (NCCSDO). NCCSDO: London (revised 2003). Download at: http://www.sdo.nihr.ac.uk/files/project/17-final-report.pdf (accessed 26/9/08).

Schofield JW (2007) Increasing the generalisability of research. In: M. Hammersley (Ed) Educational Research and Evidence-based Practice. Pp. 181-203. Sage: London.

Tew J, Gell C & Foster S (2004) Learning from Experience. Involving service users and carers in mental health education and training.

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A number of people, users, carers and members of the public, were generous with their time and taught on the module as well as giving feedback to the steering group. Thank you for your honesty and generosity: it has been a privilege for us to work with you.

Appendix 1

Members of the In our Shoes Steering Group

Clare Baguley	HEA/ Manchester University
Susan M Benbow	Professor of Mental Health & Ageing, Staffordshire University (Chair)
Will Boyce	Chief Officer, Approach
Donna Doherty	Senior Lecturer, Staffordshire University
Angela Hill	Users in Partnership/CSIP
Graham Hughes	Carer
Elaine Ivis	Regional Manager, Alzheimer's Society
Paul Kingston	Professor of Health and Social Care, Staffordshire University
Kath Morgan	User
Elaine Stanway	Centre for Ageing & Mental Health Administrator, Staffordshire University

Appendix 2

The Teaching Plan for In our Shoes

	Topic	Learning objectives	Preparation for next week
1	Introduction to the module. Relationships between users, carers & professionals	• To reflect on the relationships between users, carers and health & social care professionals • To consider what is known about what influences the relationship & implications for practice	Students interview briefly one of their clients about their experience of relationships with health & social care professionals (week 1 interviews).
2	Communication : the importance of listening and talking	• To reflect critically on the interaction between users/ carers & health and social care professionals • To reflect on what is known about ways to ensure that users/ carers can express their feelings/ needs/ desires to professionals • To consider how professionals can improve their skills in listening to & understanding users & carers	Students to interview a user or carer or user and carer dyad about their experience of care and how person centred it has been (week 2 interviews). Does the user feel that they have been treated as an individual and that their carer has been too? Does the carer feel that they have been understood and treated as an individual as well as their relative?
3	People not patients 1: getting to know the person	• To critically examine professionals' interactions with users/ carers in relation to whether or not they are person-centred • To reflect on different ways of being more person-centred	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
4	People not patients 2:	• To reflect on how person centred current practice	Students to interview a user/ carer or user/ carer

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

	tailoring care/ services to the individual	is and ways of making practice more person-centred	dyad about how far they feel professionals understand their difficulties and feelings (week 4 interviews).
5	People not patients 3: acknowledging the experiences & needs of carers	• To reflect on the role of the carer when professionals have contact with users and how far their own needs are acknowledged and reflected in care plans	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
6	Choice: being realistic about choices when resources are finite	• To consider whether users/ carers are currently given choice in their interactions with health & social carer professionals • To reflect on what choice might mean for users and carers and how practice might change as a result	Students to interview (week 6 interview) a user/ carer or user/carer dyad about their journey: in what ways have they experienced continuity of care and what ways do they feel care has been fragmented and discontinuous. How would they like to see things change?
7	What is important to users & carers?	• To consider during an interaction between a user, carer and professional what is important to each and how they influence the outcome of the contact • To reflect on ways to make the users and carers wishes more powerful in the system	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
8	Continuity of care: the 1:1 relationship & time	• To reflect on the patient journey and the importance of continuity of care to users/ carers • To consider the advantages and disadvantages of continuity of care for all parties involved • To consider how the 1:1	Students to reflect on what they wish to do differently in future and how they would like their service to change in order to address the needs of users and carers.

		relationship between professional and user/ carer fits into the complexities of modern health & social care	
9	The role of the environment	• To consider the role of the environment in how a user/ carer presents themselves to professionals • To reflect on ways of understanding the changes that people exhibit in different environments • To consider what this means for professionals in their contacts with users/ carers	Students to interview a family who have had contact with their service about how far they feel they have all been able to be involved & have their needs/ wishes/ anxieties addressed (week 9 interview). How do they feel professionals could do this better?
10	How to work with differing perspectives	• To consider how to acknowledge & take account of the differing perspectives of those involved when working with service users • To reflect on how practice might need to change as a result	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
11		• READING WEEK	
12	Sharing experiences: learning from each other	• To reflect on every contact between professional and users/ carers as a learning experience • To consider how learning can be maximised for all parties involved and how this might impact on professionals' future practice	Look through your notes on the reading list items you have read and bring them along next week to the feedback session.
13	Looking backwards to look forwards	• Review and reflection on the module • To consider ways to put learning into practice and how to continue learning into the future	

Appendix 3: Student Feedback Form

FEEDBACK FROM WEEK N: IN OUR SHOES

Please indicate your rating on the line:

1. How informative did you find this session?

    10   0

Extremely   Not at all informative

informative

2. How interesting did you find this session?

    10   0

Extremely   Not at all interesting

interesting

3. How enjoyable did you find this session?

    10   0

Extremely   Not at all enjoyable

enjoyable

4. How helpful was this session for your professional practice?

    10   0

Extremely
helpful   Not at helpful

5. How actively did you feel you participated in this session?

    10   0

Very much   Not at all

6. How well did you prepare for this session?

    10   0

Very well   Not at all

7. How would you rate the session overall?

    10   0

Extremely
good   Extremely
poor

8. What do you think you might do differently in your professional practice as a result of this session?

9. What would you suggest we do differently next time?

Please add any other comments you have below. Thank you.

Appendix 4: Teachers' Feedback Form

FEEDBACK FROM TEACHING ON THE "IN OUR SHOES" MODULE

1. How did you feel the teaching went?

2. Were you properly looked after while you were at the university?

3. Were you given a claim form to claim expenses etc?

4. What could we do better in future for people who are teaching on courses at the university?

5. Were the students respectful and interested?

6. Did you enjoy yourself?

7. Would you teach again if we run the course in future?

8. Please add overleaf any other comments that might help us improve the experience for users, carers & others who come to teach.

THANK YOU

Appendix 5: Outputs from the Project and Related Work to July 2008

Published papers

Benbow SM
Wearing purple. EFTA Newsletter (2007) November, no 3. Download from:
http://www.eftacim.org/doc_pdf/benbow.pdf

Benbow SM, Taylor L, Morgan K
Multiple perspectives: Involving users and carers in educating health and social care
professionals.
Quality in Ageing (2008) 9(2): 12-17

Presentations

Users Teaching in Partnership
Oral presentation by SM Benbow at Users in Partnership Christmas meeting,
Birmingham, 15 December 2006.

User and carer led teaching: an innovative development at Staffordshire University.
Poster presented jointly by SM Benbow, P Kingston, J-A Andrews and A Hill at the
European Regional Meeting of the International Psychogeriatric Association,
Multidisciplinary Approaches to Psychogeriatric Care, Istanbul, 3-6 May 2007.

Different voices: users and carers as teachers
Poster presented jointly by L Taylor, SM Benbow and J-A Andrews at the The Pilgrims
Progress: the pathway to better care in Geriatric Psychiatry, Santiago de Compostela,
Spain, 20 - 23 June 2007.

Wearing purple.
 Invited sub-plenary presentation by SM Benbow at the 6th European Congress of Family
Therapy & 32nd Association for Family Therapy and Systemic Practice UK Conference,
Scottish Exhibition and Conference Centre, Glasgow, 4 – 6 Oct 2007.

Standing in our shoes: teaching with a difference
Joint showcase presentation by SM Benbow, W Boyce, A Hill & J Wenyss at Authenticity
to Action, Grange-over-Sands, 8 Nov 2007.

Walking the Path Together: the important teaching role of users & carers.
Joint oral presentation by SM Benbow and K Morgan as part of Symposium co-chaired by
SM Benbow and M O'Connell at the International Psychogeriatric Association Regional
Meeting and Faculty of Old Age Psychiatry residential conference 9-11 April 2008.
Dublin, 10 April 2008.

In our Shoes: Involving individuals with dementia and their carers in delivering teaching.

Oral presentation by SM Benbow and K Morgan at HEA Mental Health Special Interest Group meeting, Meaningfully Involving Service Users & Carers in Learning & Teaching. Kings College London, 16 April 2008.

Learning from Service Users.
Oral presentation by SM Benbow at half day conference Vulnerable Older Adults as part of The Health Factor 2008.
Staffordshire University, 23 April 2008.

In our shoes: users & carers teaching
Joint oral presentation SM Benbow, W Boyce & K Morgan at HEA Workshop Piecing together the jigsaw: sharing experiences of involving users & carers in education.
Staffordshire University, 25 April 2008.

Resources on the In our Shoes website

Resource List from In our Shoes Module January 2008

Videocast of talk by K Morgan at recruitment workshop

Kath's Ten Top Teaching Tips for Users and Carers

Interim Report to the HEA

Final Report to the HEA