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The Service User and Carer Working Group's Journey Through the ALPS Programme

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The Service User and Carer Working Groups journey through the ALPS Programme
Caroline Plews, Christine Rhodes, Sue Sherwin & Jools Symons
Long and winding road
Strategic Aims

• to develop and improve assessment and thereby learning in practice settings for all Health & Social Care students
• to develop the competence of people who support and assess Health and Social Care students in practice settings
• **to enhance the role of service-users and carers in assessment and learning in practice settings**
• to develop effective project management, evaluation and partnership working
• to research and disseminate assessment practice
• to respond to and influence national and international policy and culture in assessment
How ALPS works

Partner Site Implementation Groups (PSIGs)
- Bradford
- Huddersfield
- Leeds
- Leeds Metropolitan
- York St John

- Core Team
- Dissemination & Impact Group
- IT Group
- Research Group
- Monitoring & Evaluation Group

- Joint Management Group
- Partner Lead Group

Advisory Board
In the beginning
Lines of Communication

One way
Drawing Board

• Terms of reference
• Two way communication
• Operational plan
• Work streams
• SU&C representation
Remuneration

• Different payments at each institution
Flow of information

SU&C
ALPS Good Practice Guidelines

http://www.alps-cetl.ac.uk/essen/player.html
Collaboration between the partners

• What were our goals?

• Context of development

• Different levels of involvement between the Universities

• Examples of collaboration
SHARED GOALS

- INVOLVEMENT OF SERVICE USERS AND CARERS IN ASSESSMENT OF PRACTICE
- DEVELOP COLLABORATIVE RELATIONSHIPS WITH SERVICE USERS AND CARERS
- DEVELOP FRAMEWORKS THAT SUPPORT BEST PRACTICE FOR INVOLVEMENT
- DEVELOP INVOLVEMENT OF SERVICE USERS AND CARERS IN ALL ASPECTS OF EDUCATIONAL DELIVERY
- CHAMPION CULTURAL CHANGE AT AN INSTITUTIONAL AND INDIVIDUAL LEVEL
THE GARDEN OF INVOLVEMENT .......... NOW
THE GARDEN OF INVOLVEMENT ........... THEN
DIFFERENT STAGES ON THE LADDER OF SERVICE USER AND CARER INVOLVEMENT

- Full Involvement
- Partnership
- Consultation
- Tokenism
- No Participation
DEVELOPING FRAMEWORKS FOR SUSTAINABILITY
DEVELOPING FRAMEWORKS

- Development of service user and carer role: job descriptions, possible models, development plans.
- How to develop networks with local people and communities.
- Legitimising the role: pay policy, service user and carer strategy.
- Sharing ideas: research, audit, data base innovative practice.
DEVELOPMENT OF INVOLVEMENT OF SERVICE USERS AND CARERS

- Across all Universities:
- Increase in the number of service users and carers involved
- Increase in the *types* of activity in which they are involved
- Individual and organisational change in culture
Where are we now?

FULL INVOLVEMENT
PARTNERSHIP
CONSULTATION
TOKENISM
NO PARTICIPATION
Competing drivers for the future

- Service user and carer agenda continues.
- Decreased resources in Universities.
- Future collaboration will require new goals to continue developing different types and levels of involvement.
“What Matters to US”
What Matters to US (Users of Services) in Shared Care and Decision Making
Rationale and Context

• Health policy requires future professionals to support patients and carers in self-care, including decision making

• Working effectively in partnership needs appreciation of what patients and carers can do/ofer and ability to respond flexibly

• History of collaboration of these four West Yorkshire Universities in establishing Patient Learning Journeys and support for effective working with patients and carers, modelling this for learners
Rationale and Context

• ‘Back to basics’ urge of those who had been working with users and carers and were thus thinking more outside their professional silos

• The CETL ALPs (Assessment of Learning in Practice Settings) call for research proposals to inform their competency framework and assessment methods
Research Aim

• To establish the essential skills and attributes that health & social care practitioners require to enable service user participation in decision making about their care.

• Funded by Assessment & learning in Practice Settings (ALPS) programme – Centre for Excellence in Teaching & Learning (CETL) project.
Aims and Methods

• To establish a collaborative inquiry process with users and carers to explore what professionals need to do to help patients and carers play *their* part in shared care and decision making.

• To conduct a Delphi-type exercise to widen the inquiry to other users and carers, practitioners, students and academic teachers.

• To establish implications for the assessment of students in the practice setting and practice related learning in the academic setting.

• To build on these processes to co-design and test one or more assessment methods.
Action Learning Groups

- Users and carers (US group) met 3 times in 3 groups and then all together, reflecting on experience

- Groups led by user and carer (university-employed) involvement workers

- All participants had been through Patient Learning Journey programmes

- Meetings were recorded, reflected upon and analysed in iterative process
Emergent Findings

**Time:** ‘too much pressure on staff, they are not allowed to care due to time restrictions-high stress levels-this eventually makes them bail out

**Respect and Person-centred:** ‘The Nurse listened and understood where I was coming from. She looked at things from my point of view-I needed someone to listen to me and hear what I was saying to find a solution-she really wanted to help’.

**Communication:** ‘Speak at our level but don’t assume our level. I really want to know you’re listening’
Emergent findings continued…

- **Power**: ‘As his carer I know more things about him than they do’. ‘Both Dr and Patient are experts so should work together’

- **Team working**: ‘communicating with other professionals to smooth our way to getting help’

- **The Organisation**: ‘OT very young and very open minded—not worried about ticking boxes and pleasing management—no doubt this will have to change’

- **The relationship**: ‘The Consultant was very apologetic—he admitted that ‘Mother knows best’—so I have great respect for him’. ‘I came out lighter because he’d listened to me and he’d lightened the load’
Learning and process outcomes

- Learning how to lead from a user perspective: university workers had to lead at the start as it was university based and our agenda, but we led from our own personal experience, not from our professional title.

- Learned to encourage dialogue so the group grew their ideas: ‘I learned how to listen, really listen, again’.

- Effect on those involved (i.e. usual health, wellbeing and employment outcomes) enhanced by contributing more fully from the beginning: what is important to assess?

- Users and carers can add vital depth and breadth to understandings from professional silos if given resources.
Learning and process outcomes

- Still struggling with contradictions of different research paradigms! Still working on....

- Action Learning groups with service users /carers, tape recorded and transcribed.

- Thematic analysis – statements related to shared care and decision making formed basis for a survey.

- Survey statements taken back to Action Learning groups for approval.
Survey

- Survey sent out to 3 stakeholders –
  - Service Users/ Carers – wide range of experiences.
  - Students – across 16 professions
  - Academics – across 16 professions
- Statements ranked or rated option to add comments
- Colour coded to enable attribution of response to stakeholder group.
Sample Question

Do you feel that how a person dresses makes a difference to their treatment by professionals?

Please tick one of the boxes opposite.

Yes  □
No   □

If you answered ‘yes’ please could you explain this a little below:
Sample Question

Please rank the following attributes of professionals from the most to the least important to you, where 1 is the most important and 6 is the least important:

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being honest</td>
<td>1</td>
</tr>
<tr>
<td>Being flexible</td>
<td>2</td>
</tr>
<tr>
<td>Being up-to-date</td>
<td>3</td>
</tr>
<tr>
<td>Avoiding jargon</td>
<td>4</td>
</tr>
<tr>
<td>Being down to earth</td>
<td>5</td>
</tr>
<tr>
<td>Listening</td>
<td>6</td>
</tr>
</tbody>
</table>
Broad Outcomes of resulting modified Delphi

- Satisfactory return rate
- No major surprises in the analysis to date
- Data confirms previous work by US ALG groups:
  - It is not just knowledge, skills and attributes that are important
- Many extraneous factors affect interactions.
QUESTION 5
It is important for professionals to behave in a way that marks them out as different from patients/service users and carers:
Some Findings

QUESTION 6
Professionals should check if a person can or cannot understand what is being discussed:
Outcomes

• Different perspectives – handwashing – much more than hygiene function – issue of respect.

• Dressing up for an interaction with the Doctor

• Rituals
Limitations

- Researcher influence – interaction with service users/carers
- Validity - Transferring dialogue into statements for survey. Eroded validity
- Ambiguous statements open to different interpretation.
- Uniqueness interaction – not transferable.
Value

- Service user led/ focused research.
- Richness in the dialogue - Audio clips effective way of demonstrating patient/ user opinion.
- Collaborative work- strength in numbers.
- Use of self – iterative reflective methodology.
- Intuition - facilitators were embedded in service user interactions
Next steps

- Dissemination
- Write up
- Reusable learning objects – pod casts.
- Value of talking to one another.
- Continue collaborative working.
Acknowledgements and contacts

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  ➢ www.alps-cetl.ac.uk

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Conclusion: Overall Successes of SUCWG

- Collaboration
- Community of Practice
- Cultural Shift