



## education & training

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### Training in partnership: role of service users with intellectual disability and carers

#### SUMMARY

The participation of service users with intellectual disability and carers is essential in medical and psychiatric training at all levels. It validates the training experience provided by incorporating service users' and carers' perspectives and their experience of mental illness/challenging

behaviour, anxieties, interactions and feelings generated when dealing with professionals involved in their care, and also provides an understanding of expectations, views on met and unmet needs and how management options are best explained and communicated for meaningful participation in

providing consent and in making treatment decisions. This article brings together the benefits of involving service users with intellectual disability and carers in teaching, discussing their roles as trainers, and providing practical tips to plan sessions as well as recognise and overcome barriers.

Training and teaching in psychiatry in general and learning disability in particular until recently, like other areas of medical education, was dominated by learning about the causes, prevention, intervention and clinical management of illness and cures of disease with little involvement of service users and carers. However, this is changing gradually as service users and carers are taking a more active role in making decisions about their own health-care. The shift towards the greater involvement of carers and service users in training is to a large extent value-driven, and represents a change from stated and implicit values that have been in place in training environments.<sup>1</sup> The participation of service users and carers is essential to bring into training: their own perspectives and experiences of mental illness and challenging behaviour, expectations, met and unmet needs in the management of their condition, anxieties, interactions and feelings generated and shared with professionals involved in their care. This has the potential to add real value to training compared with when it is delivered by professional trainers alone. Medical education programmes both undergraduate and postgraduate need to respond to training needs and acquiring patient-centred competencies, in partnership with service users and carers, in designing curricula and provisions of training. Areas that have been particularly identified<sup>2</sup> that also apply to people with intellectual disability include: provision of information; education in prevention and health promotion; communication of risk; shared decision-making; and facilitating self-care.

Service users and carers have been involved in medical and psychiatric training as volunteers or participants in teaching sessions since the advent of

modern medicine and it is not a new concept in training. Charcot was well-known, during his lessons at the Salpêtrière Hospital, demonstrating symptoms and signs to medical students by bringing in 'hysterical' female patients in teaching sessions. However, rather than *ad hoc* training arrangements, emphasis on issues of consent and confidentiality of participants, organised planning and formalised delivery of training by service users with intellectual disability and carers, payment of fees and expenses for participation like other teaching professionals and equality of status in teaching in line with policies and legislation need to become the norm.

#### Benefits – holistic care

Service users with intellectual disability and carers have first-hand experience of how the health and social care system works rather than how it is thought to be working by professionals and hospital management. It is known that training in partnership with people with intellectual disability and carers as trainers brings in important elements such as developing true empathy and appropriate professional attitudes<sup>3,4</sup> by helping trainee doctors to develop a better understanding of doctor–patient relationships. It would also contribute to clinicians having a better understanding of the rights of individuals with intellectual disability, respecting independence, choice, affording inclusion and active participation in decisions regarding management. Trainees have the opportunity to recognise the experience of distress and unmet needs of service users and carers, which can be an empowering and validating experience, etched in memory



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for a long time. Carers may also have extensive knowledge of common and rare syndromes and conditions with both specialist and shared knowledge of the clinical syndrome (having accessed self-help groups) that can urge the trainee to extend their own horizons of knowledge and skills.

### Policies, legislation and social drivers for change

Service users and carers can be called upon as 'experts' with unique knowledge of their particular circumstances and needs in the context of their clinical syndrome/condition, impairments and handicaps. In recognition of this expertise and the role of service users and carers, since the early 1990s due importance has been given to service user and carer involvement in UK government policy.<sup>5,6</sup> The *National Service Framework for Mental Health* which includes adults with intellectual disability proposes that 'service users and carers should be involved in planning, providing and evaluating training for all health care professionals.'<sup>7</sup> The Department of Health launched the 'expert patients programme' in 2001, highlighting the knowledge people with chronic disease have to contribute to disease management and thereby to training. The Wanless report envisaged targeted health promotion and disease management with direct involvement of patients and the public.<sup>8</sup> Since September 2005, the Royal College of Psychiatrists has made it a requirement to involve service users and carers in MRCPsych courses, for training programmes to be accredited. Medical careers and the Postgraduate Medical Education and Training Board encourage professionals to involve service users and carers in training. There is a move to deliver more services in a primary care and community-based settings to make care more accessible and available.<sup>9</sup> *A Framework for Action*<sup>10</sup> recognised the need to listen to service users' experience and expectations in order to forge a new partnership with health professionals, leading to patient-led services thereby being able to provide services responsive to needs.

In a review, Coulter & Ellins noted that most patient-focused intervention studies indicated that service users want more information than they currently receive.<sup>11</sup> This is particularly relevant in sub-specialties such as learning disability where the evidence base for therapeutic interventions is rudimentary and largely built on consensus of practice experience. With greater access to information available on the internet, rising expectations of what healthcare services should provide and deliver, less deference towards authority and a perceived hierarchical structure and greater individualism, service users and carers are seeking more answers about their clinical condition, treatment options and provision of services as well as autonomy in making decisions about care in partnership with professionals.<sup>12</sup> Health inequalities in care have been identified particularly in people with intellectual disability and people with mental health problems, who are more likely to experience major illness,

to develop them at a younger age and die of them sooner than other citizens.

### Teaching and training in partnership

Service users with intellectual disability and carers can directly or indirectly participate in teaching and training health professionals. This may be in the form of live teaching and training sessions or helping in planning the course for all grades of training including induction, but particularly through grades of core training and higher specialist training in learning disability. Other aspects of medical training where involvement could be useful are planning evaluation, review and management of courses, assessments and examination of students and specialist trainees in the psychiatry of learning disability, recruitment and selection of students and doctors.

Service users with intellectual disability and carers may participate in presentations jointly with healthcare professionals, or act as facilitators in seminars or workshops or participate in small groups. The aim would be to integrate the perspectives of service users with intellectual disability and carers in the content of the course.

It is important that service users and carers feel comfortable and identify themselves as part of the training team and on a equal footing with other members of the training team, providing input in planning and designing modules. Resources that we may not automatically consider such as library access and administrative and information technology support need to be provided for service users and carers. The format of presentation may be different for example service users and carers will not put their life story on a powerpoint presentation, but may prefer a conversational or question and answer style<sup>1</sup> or bring a life story folder with photographs and a collection of relevant material to share with the trainees.

Other practical measures that can help run an effective programme include: ensuring that the programme is focused on learning with service users and carers in mind, offering lunch and regular breaks, avoiding lengthy sessions and ensuring participation for appropriate periods of time that are meaningful rather than tokenistic and based on actual need. It is also useful to have feedback sessions and periodic strategy meetings for service users and carers in order to optimise the training programme. Needless to say, such meetings would need to be arranged at convenient times and suitable venues. Participants would need to be encouraged to provide regular feedback of their own experiences perhaps by completing feedback questionnaires, thereby moulding and shaping the teaching programme as the course progresses. Other methods may include role playing, problem solving or enquiry-based learning that could form part of observed structured clinical assessments (OSCEs). Additional methods of adult learning such as facilitating group discussions of trainee experience, service user/carer-led meetings and use of reflective writing to inform the group discussion thereby enriching the learning experience, also need to be



considered. Moreover, developing educational aids such as video clips, web-based resources and tools can be useful. It is also useful to have a pool of trainers for support, for feedback of the training programme and also bringing into training views from a wider reference group such as the Down's Syndrome Association and local service users and carers groups.

## Assessments and appraisal of trainees

People with intellectual disability and carers may be able to provide feedback on assessments of attitudes, bedside manners and skills of trainees having received appropriate training. It is important that people with intellectual disability and carers are comfortable about doing assessments and feel reassured that their participation will not influence their treatment in any way.

## Meaningful participation

Tokenistic participation by people with intellectual disability and their carers is of little value and it is important to ensure that participation is meaningful. A culture of mutual respect that considers the perspectives and contributions of people with intellectual disability and carers as that of a teacher, and in no way less equal in value to other teaching professionals, needs to be established. Practical measures such as providing training and support to people with intellectual disability and carers to feel competent in delivering teaching with the predetermined learning objectives in mind need to be put in place. There needs to be a system for recruitment and an identified specific fund for reimbursing expenses and payment of fees incurred in teaching.

Feedback from people with intellectual disability and carers involved in teaching can be useful in validating their own experience as noted in the excerpt where D.C. and S.K. are service users with intellectual disability talking about their experience in teaching (Box 1).

## Barriers that can be overcome

It has been noted that paternalistic attitudes are the biggest barrier to patient empowerment and creating more equal relationships between patients and professionals. Lack of information to go on planning courses, along with fears and anxieties about working with people with intellectual disability and carers, can sometimes obstruct successful involvement. People with intellectual disability and carers can sometimes be seen not to qualify for a training team on the basis that they do not represent the 'typical' patient or carer in their group. Nevertheless, in reality, users/carers are often able to share not only their own experiences, but also the experiences of their peers and other people whom they have met in patient forums or support groups.

Some practitioners find it difficult to accept users/carers as teachers, fearing that doing so will have an adverse impact on their relationships with their patients; detailed knowledge about their own illnesses might also present a threat – some professionals might fear losing

### Box 1. Feedback from two service users with intellectual disability

Question 1. How did it feel being part of the teaching programme?

D.C.: It felt good. I've done it before and was comfortable doing it. I like doing anything like that.

Question 2. How do you think your contribution helped with teaching?

D.C.: It showed we can do it. It's better coming from us because we're in it.

S.K.: When talking to the patient, students must speak slowly and clearly. They should understand what is going on. Students should answer any questions the patient may have. Students must take time to speak with the patient, not to rush or make the patient feel unimportant.<sup>13</sup>

their status as experts on health matters. Often, power is perceived as a key element of the culture of pedagogy and maintenance of that power is often perceived to be important by traditional teachers.<sup>14</sup> Other criticisms include fear that training may 'professionalise' users/carers thereby losing their ability to make valuable contributions through education. Some also argue that users/carers in their teaching role may feel that they have a special relationship with consultants and are entitled to privileged care; at other times the criticism may be one of exploiting vulnerable people. These barriers can be overcome by ensuring users/carers have a real choice in making a decision and are well supported, facilitating communication and obtaining informed consent for agreement to participate in the teaching programme. Course organisers can seek recommendations from service user/carer groups and voluntary organisations to recruit more than one service user/carer – it may be worth recruiting a group of people bringing in value to the teaching programme due to the wider range of experiences. Limiting the number of times a user/carer participates helps to maintain the sense of 'freshness' and avoids possible overcommitment and fatigue. Diversity needs to be valued and minority viewpoints and experiences should be reflected in the teaching including addressing issues relating to ethnic minorities. Confidentiality needs to be maintained by all concerned.

People with intellectual disability and carers may experience feelings of stress and anxiety as a result of participating in teaching, and may feel isolated and left out of the core teaching group, may find medical terminology incomprehensible and layout of settings for delivery of teaching all too upsetting. Some service users reported teaching sessions to be a source of anxiety reinforcing their feelings of ill health, whereas others had concerns about students having access to their medical notes.<sup>15</sup> Offering users/carers ongoing training, debriefing sessions, networking in groups and providing support to help ease feelings of stress, anxiety and isolation and simplifying medical jargon can go some way in helping participants. A setting easily accessible by public transport is important. A designated person from



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the teaching faculty needs to be entrusted with the well-being of the person with intellectual disability and carers presenting, greeting them on arrival, familiarising them with the place including showing them the cloakrooms/facilities and the venue and be available to support the service user and carers. Arrangements for claiming fees and expenses need to be in place, and these may be adapted locally.

### Practical tips

Pre-planning of teaching sessions is extremely important for the success and meaningfulness of the programme. From the broad curriculum design phase to the planning of individual teaching sessions, it is worthwhile ensuring that service user/carer training sessions fit in and complement the training session. Within the time allocated for the session, the specific objectives for delivery by the user/carer need to be discussed and carefully planned. Having a good chair to ensure optimum use of time and discourage insensitive and inappropriate questions or remarks is useful. Users and carers may choose to participate together on the same topic providing comprehensive coverage of different perspectives. Moreover, it is known that teaching that is jointly delivered by users/carers together with other teaching staff is more effective in integrating the perspectives of patients and carers within the overall course content. Debriefing and support is important for users/carers after each session and needs to be delivered by a trained person. Appropriate support and training is necessary throughout the process for service users/carers. Their role as educators is enhanced by offering courses such as 'Training the Trainers' that focus on presentation and assertiveness skills, interactive techniques and student-centred techniques.

### Conclusions and recommendations

The foundation stone for a solid partnership between users/carers and other teaching professionals is equality and mutual respect of what people with different experiences and background bring into teaching. It is acknowledged that involving service users with intellectual disability and carers in training will be in itself a learning process, as it is highly likely that there is no 'one size fits all' model that will work for all programmes in all localities. Important aspects of the partnership include obtaining informed consent before each training block, maintaining confidentiality, involving more than one user and carer, respecting diversity and inclusion of minority viewpoints and experiences, careful curriculum design and pre-planning of sessions, selecting settings that are comfortable and venues that are easily accessible, prompt

payment of fees and expenses, and systems that offer ongoing training, debriefing and appropriate support.

Recommendations include involving people with intellectual disability and carers from black and minority ethnic groups, recognising carer stress and gender differences in the burden of sharing care provision and including other underrepresented groups such as elderly people with intellectual disability. There is a need for research to evaluate the strengths and weaknesses of different teaching models to define the characteristics of a successful training programme and the impact teaching has on practitioners' attitudes and skills and on services catering to the needs of people with intellectual disability.

### Declaration of interest

None.

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