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JPN Editorial November 2013

This special issue of JPN includes three papers that put the focus of attention on the users of mental health services, not as patients but as providers of peer support services or as collaborators in mental health nursing research. In particular, they highlight some of the thought and consideration that goes into ensuring that service users and family carers are adequately prepared and supported in these relatively new roles.

SUGAR, the **S**ervice **U**ser and **C**arer **G**roup **A**dvising on **R**esearch, was formed at City University London in October 2009. Senior mental health nursing researchers in the School of Health Sciences were keen to move away from a reliance on one or two service users and fairly low level involvement in studies. They sought to obtain wider representation and a greater range of voices, including that of family and friends (carers) who support others with mental illness and they aimed to ensure that these 'experts through experience' were involved as full, collaborative partners.

The SUGAR group consists of people with lived experience of mental illness and the mental health system and carers who support others with similar life experiences. They are encouraged to draw on those experiences to inform discussions about the design and implementation of research studies and to make sense of the results and findings from those studies.

Members were recruited in the London Boroughs of Newham, Tower Hamlets and Hackney, all on the eastern, poorer side of the capital city, seeking people who were or had been users of statutory mental health services. (By statutory of course, we mean the services provided free of charge and as of right under the UK's National Health Service.) Some of the people approached had been part of a previous problem-based online educational project at the university, in which service users and student mental health nurses communicated with each other via email (Simpson et al 2008)

One of the first tasks for the group was to draw up a set of ground rules for the meetings. These aimed to provide a safe place for people to speak and be listened to in a respectful manner, no matter what their background or views. Meetings were facilitated and food and drink shared. People were paid for their contributions, albeit a small amount. The experiences reported in the article on SUGAR suggest this approach has been a great success with regular, passionate discussions taking place and benefits identified by the academic and user/carer researchers alike.

The group of service users and carers gathered together in SUGAR has been a very cohesive one. Members don't generally talk about diagnoses or each other's psychiatric 'conditions', but it is clear

from the discussions that there is a wide variety of mental health distress in the group. Some have been inpatients, some not, or not for a very long time. Some use prescribed medication, others an assortment of complementary medicines, some no drugs at all (except occasional tobacco and alcohol). There are men and women, different sexualities, a range of ages, ethnic and cultural backgrounds, of country of birth and mother-tongue, and of work history and educational attainment.

“The common factor is that (so far) we have all survived both our ‘mental illness’ and the system of treatments, medicaments and therapies prescribed for it. We have survived the attitudes of our families and friends and of the wider society. We are all well aware of the stigma attached to a mental illness diagnosis and we support any real action taken to overcome it.

“A major concern among any group of service users involved in research is that of our role. Will it be tokenistic; will the professional researchers ask questions, note the answers, use the knowledge and then forget the source? This might seem over anxious or even paranoid, but experience shows that this is too often the case. Genuine involvement and respect for views expressed is paramount.”

Two other papers in this issue focus on mental health service users as peer supporters and in particular, the provision of training, support and coaching that aims to maximise the effectiveness and wellbeing of peer workers. There is a growing workforce of peer supporters being recruited and trained to draw on their personal lived experiences of mental distress and of mental health services to provide emotional and practical support to others undergoing similar experiences. Over 27 states in the USA now employ peer support staff in a variety of roles and have collaborated to create a scoping and guidance document for peer support for use in state funded and other services (Daniels et al 2010). As Medicaid has defined peer support services as reimbursable, the workforce continues to expand (Daniels et al 2012). Similarly in the UK, where peer support workers are being promoted as the vanguard in the reform of mental health services that are aiming to re-focus on personal recovery rather than a narrower medical approach (Repper 2013, Faulkner & Bassett 2012).

But these are relatively early days for all involved, and the papers on peer support training, supervision and coaching for peer support staff provide useful behind the scenes illustrations of just how the preparation and support of this new band of workers is being planned and organised. They highlight the gains that can be made and also some of the challenges that remain or that may surface as peer support work becomes more commonplace.

Interestingly, it could be argued that peer workers are becoming more organised and recognised at the very time nurses and other professional groups are under threat as budgetary constraints and concerns about the quality of healthcare and education tops the news and political agendas (Willis Commission, 2012). Many nurses would envy the time and attention being given to the training, supervision, coaching and support of peer workers and collaborative user/carer researchers as they struggle with their own experiences of emotional labour and demands for greater efficiencies. Healthy workplace practices should be promoted for all.

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