

Users of Mental Health Services as Peer Support Providers and Research Collaborators

This special issue of the *Journal of Psychosocial Nursing and Mental Health Services* includes three articles that focus 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 the thought and consideration that goes into ensuring that service users and family caregivers are adequately prepared and supported in these relatively new roles.



SUGAR, the Service User and Carer Group Advising on Research, 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 (caregivers) 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 individuals with lived experience of mental illness and the mental health system and caregivers 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, we mean services provided free of charge and as of right under the United Kingdom’s National Health Service.) Some of those coming forward had been part of a previous problem-based online educational project at the university, in which service users and mental health nursing students communicated with each other via e-mail (Simpson, Reynolds, Light, & Attenborough, 2008).

One of the first tasks for the group was to establish a set of ground rules for the monthly meetings. These aimed to provide a safe place for individuals 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, and appointed as honorary research fellows. The experiences reported in the article, “Adding SUGAR: Service User and Carer Collaboration in Mental Health Nursing Research,” by Simpson, Jones, Barlow, and Cox (pp. 22-30) 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.

SUGAR members do not 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

Swarbrick, Brice, and Gill (pp. 41-45) aim to maximize the effectiveness and well-being 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

We are all well aware of the stigma attached to a mental illness diagnosis and we support any real action taken to overcome it.

and alcohol). There are men and women, different sexualities, and a range of ages, ethnic and cultural backgrounds, country of birth and primary language, work history, and educational attainment.

The group gathered together in SUGAR has been a cohesive one. The common factor is that (so far) all have survived both their mental distress or illness and the system of treatments, medications, and therapies prescribed for it. Members have also survived the attitudes of families and friends and wider society. We are 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 and carers involved in research is that of their 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 articles in this issue focus on mental health service users as peer supporters. “Evaluating the Selection, Training, and Support of Peer Support Workers in the United Kingdom,” by Simpson, Quigley, Henry, and Hall (pp. 31-40), and “Promoting Wellness of Peer Providers Through Coaching,” by

provide emotional and practical support to others undergoing similar experiences. More than 27 states in the United States now employ peer support staff in a variety of roles and have collaborated to create a scope and guidance document for peer support for use in state-funded and other services (Daniels, 2010). Because Medicaid has defined peer support services as reimbursable, the workforce continues to expand (Daniels, Bergeson, Fricks, Ashenden, & Powell, 2012). In the United Kingdom, peer support workers are being promoted as the vanguard in the reform of mental health services that are being re-focused on personal recovery rather than a narrower medical approach (Faulkner & Basset, 2012; Repper, 2013).

These are relatively early days for all involved, and the two articles 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 organized. They highlight the gains that can be made and also some of the challenges that remain or may surface as peer support work becomes more commonplace.

Interestingly, it could be argued that peer workers are becoming more organized and recognized at the very time nurses and other professional groups are under threat as budgetary constraints and

concerns about the quality of health care and health professional 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/carers researchers as they struggle with their own experiences of emotional labor and demands for greater efficiencies. Healthy workplace practices should be promoted for all.

REFERENCES

- Daniels, A. (2010). *Pillars of peer support: Transforming mental health systems of care*. Retrieved from <http://www.pillarsofpeersupport.org>
- Daniels, A., Bergeson, S., Fricks, L., Ashenden, P., & Powell, I. (2012). Pillars of peer support: Advancing the role of peer support specialists in promoting recovery. *Journal of Mental Health Training, Education and Practice*, 7, 60-69. doi:10.1108/20428301211205892
- Faulkner, A., & Basset, T. (2012). A helping hand: Taking peer support into the 21st century. *Mental Health and Social Inclusion*, 16, 41-47. doi:10.1108/20428301211205892
- Repper, J. (2013). *Peer support workers: Theory and practice*. Retrieved from http://www.centreformentalhealth.org.uk/pdfs/ImROC_peer_support_workers_theory_practice.pdf
- Simpson, A., Reynolds, L., Light, I., & Attenborough, J. (2008). Talking with the experts: Evaluation of an online discussion forum involving mental health service users in the education of mental health nursing students. *Nurse Education Today*, 28, 633-640.
- Willis Commission. (2012). *Quality with compassion: The future of nursing education*. Retrieved from http://www.williscommission.org.uk/_data/assets/pdf_file/0007/495115/Willis_commission_report_Jan_2013.pdf

Richard Humm
Honorary Research Fellow
School of Health Sciences
City University London
London, United Kingdom

Alan Simpson, PhD, BA(Hons), RMN
Facilitator
SUGAR
Professor of Collaborative Mental Health Nursing
School of Health Sciences
City University London
London, United Kingdom

The authors have disclosed no potential conflicts of interest, financial or otherwise.
doi:10.3928/02793695-20131126-01