

Service user leadership: training and development for service users to take the lead

Angela Newton, Anne Beales, Daniela A. Collins and Thurstine Basset

Angela Newton is a Deputy Director and Anne Beales is a Director, both are based at Service User Involvement Directorate, Together: For Mental Wellbeing, London, UK. Daniela A. Collins is a Senior Lecturer at School of Health and Education, Middlesex University, London, UK. Thurstine Basset is a Director at Basset Consultancy Ltd, Brighton, UK.

Abstract

Purpose – This paper outlines the concept of service user leadership and both describes and reflects on an accredited training programme that enables mental health service users to take a leadership role.

Design/methodology/approach – The authors argue for a service user leadership approach and the training programme is reviewed by previous participants

Findings – Service users can take on a leadership role if they are given suitable and relevant training and development opportunities. Service user led training can be transformational.

Practical implications – Commissioners of mental health services should consider how to support service user leadership programmes, which can reach places and achieve outcomes that traditional mental health services are unable to attain.

Originality/value – The concept of service user leadership is relatively new and the training programme described in this paper is both original and highly valued by participants with many significant outcomes.

Keywords Service user leadership, Peer support, Empowerment, Service user involvement, Confidence, Wellbeing, Leadership, Training

Paper type Case study

Together's Service User Involvement Directorate

Together is a national (England) charity working alongside people with mental health issues on their journey to leading fulfilling and independent lives. We believe that people experiencing mental distress can direct their own journeys towards improved mental health – our role is to give them the tools and support to achieve this. Our focus on service user involvement and leadership is at the heart of our philosophy and shapes every aspect of our work.

Together was founded in 1879 and has always placed significant importance on recovery and promoting the independence of mental health service users. Together provides support to approximately 4,000 people every month across 80 different projects. It has a broad range of services including community support, residential care, supported living, advocacy, criminal justice and court diversion schemes.

In 2004, Together created a new post and appointed a Director for Service User Involvement. This appointment led to the creation of a Service User Involvement Directorate, a team of staff and volunteers, the majority of whom have experienced mental distress themselves. The aim was to put the collective voice of service users at the heart of all decision-making. This bold step established Together's reputation of being wholly committed to service user involvement, leadership and peer support.

As a mental health charity whose focus on service user leadership and peer support is widely recognised, Together is well placed to develop and share its learning both within England and also internationally. We are able to offer a lead in these areas in an informed and sensitive manner through our longstanding commitment to working in partnership with local service user groups. This takes place through our Regional Service User Steering Groups, which bring together service users from local service user groups across the country to support each other and work together to achieve a better future.

Overcoming disempowerment through service user leadership

Service user involvement can take many forms. It operates on a continuum or ladder with passive recipient at one end and active participant at the other (Arnstein, 1969). In criticising the rather linear model of Arnstein's ladder, McKinley and Yiannoullou (2012) point out that to operate at the more actively involved citizen level, service users need knowledge and skills and confidence which are often lacking.

Critics of the term "service user involvement" often stress that it has only been through more direct action that the influence and voice of service users has grown. Campbell (2008) states:

One danger in talking about service user involvement is that it is frequently taken to mean mental health professionals involving service users rather than service users involving themselves (p. 293).

He argues for more credence to be given to service user action and Barnes and Cotterell (2012) also emphasise this point by highlighting the impact of service user, carer and local community groups in campaigning to change services and indeed pursuing other broader societal objectives that go well beyond the health and social care field.

At Together, we believe that service users need to be able to take the lead, both in their personal care and, if they want, in working to improve services. When they are able to take the lead, the journey that they embark on with their key-worker or care coordinator is one undertaken with two co-drivers. Sometimes the service user is driving; sometimes the key worker is driving. But, when the worker is driving, the service user is sat next to them telling them when to turn and which route to take.

Service user leadership is a new, but increasingly recognised, term within mental health that has emerged from the service user movement. Beales (2012) explains that service user leadership will help to ensure that the ethos of peer support is preserved within an overall framework that supports equality for service users. Service user leadership is a way of applying the combined lived experiences of people using mental health services to offer insight and lead the way in the improvement of individual lives, care and support and the development of mental health services.

In order for service users to influence the planning, development, delivery and monitoring of mental health services, they need to have the skills, knowledge and confidence to be able to do so. Perhaps one of the biggest barriers to being able to do this is service user's self belief. After many years of being told that your life would not ever be the same again, and losing many key things in your life, it can be hard to think that perhaps you can move on, that you have something useful to contribute and that other people will listen to your views and thoughts about how things could be better. This pattern of thoughts is, of course, the very nature of mental ill health for many people, and the impact that it has on your wellbeing and sense of self cannot be underestimated.

Service user leadership can take place at many different levels and takes many different forms. It can range from having more control in your own personal care and day-to-day life, to shaping the future of mental health services at a national level and everything that sits in between. The very nature of leadership and its possible impact can therefore be far-reaching.

For somebody who has used services for many years and has perhaps been subjected to detainment under the Mental Health Act, has lost control of their rights and not been able to assert themselves and make their own choices, to start taking control back can be exceptionally liberating, and yet scary at the same time. Similarly, if you have repeatedly been told that you cannot do things because it may be risky, that you should not risk being unwell again, that others need to look after you and decide what's best for you, it can be a difficult and long process to start building the confidence to think and speak and act differently.

To be confident enough to say that your anti-psychotic medication just is not working for you at the moment and you would like to try something else can be a difficult thing for many people. This is especially true when this has already been tried once only to be met with an entirely negative response. This can unfortunately still be the case. Service user leadership is knowing what you want and being able to express it and demand it when necessary. It can be life changing for people to take control of their own lives in this way.

Moving from a personal to a broader perspective, there are many people who are trying to change the system and who are asking for and demanding a better deal from mental health services. This has been happening in an organised way in the UK since the 1980s. On a local level, service user groups are having conversations with local commissioners and providers, and on a regional and national level, they are engaging with a range of government bodies. This is another form of service user leadership: the diverse and collective voice of service users improving mental health services both for themselves and the generation that will follow.

Simply put, we know what works for us and collectively we need to lead change from that perspective of insight. Together's Service User Involvement Directorate will continue to lead and influence, quietly or loudly as appropriate, for as long as it is needed – that is to say, until an entire generation has grown up knowing the real possibilities for wellbeing, regardless of their experience of distress. Our truth is based on the reality of the stigma, poverty, confusion, isolation and marginalisation that we experience. Because we live through fear, often troubled and sometimes in trouble, we know real frustration. We have begun to establish standards and ways of contributing that make a truly valuable difference, doing so on our terms, at very little cost and with courage and commitment.

Training and development for service user leadership

Together's Service User Involvement Directorate has pioneered a way of working with and alongside mental health service users. Our trusted way of working, the programme we call "Let's Work Together", enables service user leadership to flourish by bringing people together through training and volunteering opportunities. Central to the programme is peer support, and also specialist training that develops people's leadership skills and experience of being with and amongst other people who have faced similar struggles and challenges.

"Voices Together: service user leadership and peer support" is a training programme that Together developed in response to a need for service users to develop their skills in these increasingly important areas. This training is crucial as it provides a cornerstone for people to effectively take charge and lead their own lives, often also leading to people feeling more able to influence and direct the services that they access. Its origins lie with CAPITAL, a service user led group in West Sussex, which since 1997 has run a training programme for all new members. The programme was further developed in 2007 by Together. Together ran a 12-day training programme that was completed by approximately 200 people over the course of two years. An evaluation of this programme in 2009 indicated that, whilst the content, delivery style and group dynamics had been largely positive, many participants wanted to access a course that had a higher standing and status that was recognised by external agencies, educational establishments and possible employers. It was this feedback that led to the accreditation of the programme.

A successful application to Middlesex University in 2010 led to the training programme being accredited as a stand-alone module of 30 credits at level 4. This provides an indication of the level of study and commitment required in taking part.

The programme is comprised of 12 training days that focus on a broad range of themes and topics, from equality and diversity to stigma and discrimination, self-esteem and confidence to emotional literacy, meeting skills to presentations and the service user movement. Each of the training days has been carefully designed and their successful delivery depends on the skills, knowledge, expertise and personal experiences of the service user trainers that lead each session. The style of delivery means that the trainers themselves support participants to have a broad range of stimulating and interesting discussions that help build knowledge, confidence, leadership and peer support throughout the programme. Peer support and tutorial support are an integral part of the programme.

Participants have a choice of whether they would like to secure accreditation or not (it is possible just to receive a certificate of attendance for the 12 training days), though many are initially unsure of whether they wish to take on the extra requirements. The amount and level of assessed work that is required for accreditation, in addition to attending the training days themselves, can feel quite daunting, especially for those who have not been in an educational environment for some time. However, with support from the trainers, the vast majority of participants have gradually realised that the assignments are not as difficult as they first appear, and have chosen to opt for accreditation.

The assignments themselves consist of a reflective essay and a learning log. The writing style and content of these two elements are often very different. Both are often fascinating and very moving to read, as they partially focus on participants' own experiences of distress, their interpretation of this and the impact it has on their lives. Everybody is expected to complete a learning log but the reflective essay can be presented orally, or in a poster format, if participants prefer.

Middlesex University externally moderates the quality of the assessment process at Together. The course work received for external moderation has shown a very good standard of work. The students' work reflects their level of study with the reflective assignment and learning log attached as evidence of the development of participants. The work meets the required learning outcomes and everyone who has submitted work for marking and moderation to date has achieved a non-graded pass. Internal marking and internal moderation of the course work is consistent across the range of first markers and second markers. The feedback provided to students is focused on what they have done well and how they could develop their work, including their personal and professional development. This provides reflection on student's own survival as service users and their strengths that come from their experiences of being mental health survivors. This is a useful aspect to their learning about service user involvement and leadership.

The programme's service user trainers are able to not only support, but also witness the transition, and in some cases transformation, of individual participants, watching them find their voice, tap into their strength and blossom along the way. To enable people to move forward in their lives so powerfully through the delivery of a training course is, in itself, incredibly rewarding. As the programme lead has said:

The beauty of the course is that it treats each person as an individual, enabling them to explore their thoughts and feelings in a safe, supportive and inspirational setting with their peers. Through this experience, people find that they not only feel more in control of their own lives and their own destiny, but begin to form allegiances and alliances with others. Many then become a force to be reckoned with as they go on to inspire and motivate others and become leaders within their own lives, localities and regions.

Review of the training programme

A series of telephone interviews with previous course participants was conducted in 2012 to review the impact of the training programme. The interviews were conducted by Together, but not by any staff members who had directly contributed to the training programme. We received the following feedback from participants:

The training helped me get my confidence back.

I gained more confidence to face difficulties in everyday life.

It makes you think in ways you never thought of thinking.

It gave me a feeling that I could do more [...] and voice my opinions [...] I feel so physically and mentally well.

I feel more powerful and more assertive.

The environment enabled me to improve [...] my confidence was optimum, my thinking and ability to reason and rationalise were optimum [...] whilst on the course I felt really confident and really calm [...] really able.

I can ask other people and I'm more open about what help I need.

The training helped me re-harness the skills and knowledge that were previously there [...] it reinvigorated me [...] it enabled me to do a lot more.

I feel I could cope with most anything.

It helped me explore other courses.

It's made me healthy. It's made me look at life in a different way than I thought I ever would [...] I'm in the best place I've ever been.

They did turn my life around [...] I met some great people, loads of friends, through the training.

If I hadn't done it, I'd still be out there not knowing which way to turn [...] it boosted me to try and find a job and that's what I now do with the charity down here.

We were struck by the strength of this feedback and the evident impact of the course on people's lives. We are aware that this method of gaining data to evaluate the impact of the programme is not very robust. However, it is at least a start.

In looking to compare our findings with papers written about similar learning programmes, we were unable to find much published material. A lot of papers have been published about the involvement of service users in the training of mental health workers (e.g. in this Journal: Tickle and Braham, 2012; McCusker *et al.*, 2012) but very few about the training of service users to equip them to carry out such roles. An exception is the description and critique of the "Changing Minds" programme, which aimed to equip service users to deliver mental health awareness training (McKinley and Yiannoullou, 2012). This programme measured mental wellbeing and was shown to have the greatest impact on the participants' self-esteem, confidence, optimism and their ability to develop supportive networks, challenge discrimination and obtain voluntary and paid employment. These broad outcomes, which go much wider than an ability to deliver awareness training, are mirrored in the feedback that we collected.

We were also encouraged to read about the development and delivery of a self-management and peer support training programme across Wales (Crepaz-Keay and Cyhlarova, 2012) and look forward to the publishing of their outcomes in relation to wellbeing, ability to function on a day-to-day basis, goal achievement and cost effectiveness.

Many participants on our "Voices Together" training programme also used it as a springboard towards specific achievements and goals. The doors that the training has opened to participants are numerous, with people:

- speaking at AGMs, Universities, conferences, county council meetings;
- taking on leadership roles, in relation to the service they attend, for the service to become more user led;
- becoming co-facilitators on subsequent training programmes;
- taking on the role of chair, treasurer or becoming a member of the board in both national and local voluntary organisations;
- completing other training courses;
- changing jobs to something more suitable and rewarding;
- lobbying, campaigning and advocating; and
- taking on voluntary work.

The future

To date, approximately 320 people have accessed the training programme. Of these, 43 have accessed it since it became accredited, and of the 15, who have chosen to complete and submit assessments, nine have been awarded a Pass mark and a remaining six are expected to achieve a Pass within the next few months. This 100 per cent pass rate is something that Together is particularly proud of. A further 32 people are currently accessing the training programme, of which we expect approximately 16 to complete, submit and pass assessments.

Measuring the impact of the Voices Together training programme has been crucial, and enabling participants to share the impact of their learning experience in their own words is the only real way in which it can be understood by others. We are currently looking at ways to measure impact that go beyond the feedback we have sought to date.

We also hope to read of other such initiatives in future journal papers. This would seem a very likely outcome of initiatives such as the establishment and running of Recovery Colleges in the UK (Perkins *et al.*, 2012).

The demand for Voices Together is undoubtedly high as the value of the lived experience of service users becomes increasingly recognised. However, the ability to meet this demand is becoming more and more difficult as mental health budgets become tighter and access to service user led training for service users becomes more difficult.

This is a current issue for the future of service user leadership, and particularly so for black and minority ethnic (BME) service users. Kalathil (2011) has assessed BME mental health service user involvement and is concerned that it is decreasing within the current economic climate. This concern is also raised by Yiannoullou *et al* (2012) who see opportunities for BME service user leadership, despite some examples of good practice, as declining.

On a brighter note, the success of Voices Together and the recent emergence of peer supporters within health and social care have led to the development of a Peer Support Training Programme. This service user led training programme has been piloted and Together has very recently secured accreditation for it with Middlesex University. There is a high demand for a service user led, non-medicalised and holistic training programme to develop the understanding, knowledge, skills and confidence of peer supporters to offer support to their peers during distressing times. We hope that, now this training programme has achieved accreditation, it will open up other avenues and possibilities for the accumulation of learning and associated credits for people with lived experience of mental health issues.

These learning and development opportunities underpin Together's focus on service user leadership. Service users have a proud history of working together to make a difference (see Survivor History: www.studymore.org.uk/mpu.htm). We know our vision for tomorrow: given the right opportunities, training, support and development, we can lead the way to a better future.

The last words in this paper are from a group of participants in a recent "Voices Together" training programme in Grays, Essex, in 2013. At the conclusion of the programme, participants were asked for their definitions of service user leadership. They said that for them service user leadership was:

- Giving guidance and solid advice to others in need, using learned experience and understanding.
- Being a proactive member of society, leading by example, being a shepherd not a sheep.
- Leading by example and guiding rather than pushing.
- Facing your challenges head-on and feeling proud of your accomplishments.
- Using your personal skills and experience to empower others and give them a voice.
- Confidence, compassion and personal belief in change where change is needed.
- Showing initiative.
- From a personal point of view, this course has given me greater confidence within groups and more specifically with public speaking. Leadership for me is about control within life and the ability to take control and move forward with confidence and help others when I can.
- How leadership works

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Corresponding author

Angela Newton can be contacted at: Angela-newton@together-uk.org

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