The Value of Lived Experience: Co-Production and Collaboration in Recovery Colleges

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Introduction

Recovery Colleges are a move away from traditional mental health services, instead focusing on an educational approach and on individual strengths and abilities. Their aim is to support individuals to become experts in their own lives,¹ shifting the idea that mental health professionals are the experts and service users are passive receivers of care. Recovery Colleges are based on the principle that all are equal, regardless of whether they access mental health services, care for a loved one or are a mental health professional. In College, all are learners. Recovery Colleges present the possibility of transformation in the lives of people with long-term mental health conditions, the possibility of living a life with a sense of purpose and meaning and the chance of an improved quality of life. Evidence shows that learners attending Recovery Colleges have a greater sense of hope for the future, increased confidence in their abilities, opportunities to develop themselves and a wider social network.²

Personal Recovery

Recovery is a personal journey and one that cannot be prescribed for an individual. Hope has been recognised to be at the heart of personal recovery and is a driver for an individual to take on the challenge of rebuilding their life with meaning and purpose.³ Alongside hope, being able to make use of opportunities and to take control of one’s life are also important aspects of personal recovery.

Recovery has different meanings to different people, but it is a lot more than simply treating or reducing symptoms.² Personal recovery is led by the individual and isn’t about finding a cure for mental distress. Instead, it is about living a meaningful life, feeling able to contribute and living a satisfying life in the presence or absence of symptoms.⁴ Personal recovery is about seeing the individual for who they are, not a collection of symptoms or a diagnosis. This is a move away from traditional psychiatric
care in which recovery is equated to ‘cure’ and many mental health conditions may affect individuals throughout their whole life. Recovery belongs to the individual, rather than being 'held' by the service or by mental health professionals. In many ways, the concept of recovery can be difficult for some to relate to or understand, particularly as “recovery does not refer to an end product or result”; it is, for many accessing secondary care mental health services, a lifelong journey. All too often, mental health services only focus on the deficit or the illness, and mental health services are there to manage an individual’s illness. A focus on personal recovery and being person-centred in our approach to mental illness allows individuals to take control and ownership of their own recovery. Patricia Deegan talks about how mental health services ‘dehumanise’ individuals by focusing only on a diagnosis which can lead to apathy and disempowerment for both individuals and for staff working in the mental health system; and it can be difficult to realize our true potential. Person-centred approaches enable the power balance between individuals who use mental health services and mental health professionals to be redressed and a partnership to be developed, with the service user leading their own recovery, supported by their mental health care team.

**Recovery Colleges**

There is a growing evidence base about the efficacy and value of Recovery Colleges, and they are growing in popularity. Recovery Colleges were first developed around six years ago, and there are now around 40 Recovery Colleges across England and the UK. ImROC (Implementing Recovery through Organisation Change) is the leading organization that guided the development of Recovery Colleges and outlined eight core principles that Recovery Colleges should aspire to achieve. Many of the Recovery Colleges are aligning themselves to the ImROC core principles. This approach to mental health support is a move away from traditional support offered to mental health service users, which have previously been in the form of day services where activities are prescribed for an individual. The difference with Recovery Colleges is that service users have the choice about what they do: they can choose if they want to attend college and what classes they sign up to. The idea that progression is possible and that individuals will be supported to move forward is an integral part of Recovery Colleges.

The fundamental basis of Recovery Colleges is the belief that we all have something to contribute. It is a strengths-based approach with learners being encouraged to focus on what makes us unique and is founded on individual strengths. This is opposed to a traditional a mental health illness model, which tends to focus on what an individual has lost; and this can be disempowering. Focusing on strengths can be a challenge for some, as mental health services tend to focus on illness, symptom reduction and what the individual may be unable to do at that point in time. There is a transition for people who use services (and have done for a long time) to be seen as an individual with unique skills and abilities; often people’s identities are strongly linked with a diagnosis or being a patient. Recovery Colleges foster an environment of support, based on the belief that we all have something of value to offer, everyone is equal and is focused on individuals' strengths. There is a shared understanding that there is the commonality of mental distress that has brought all learners and those working in Recovery College together; whether it be an individual experience, an experience of supporting a loved
one or working with individuals who have experienced distress, or a combination of all three. Learning in a shared environment allows students to be themselves, rather than wearing a label of mental distress. The beauty of Recovery Colleges is that the focus isn’t on a particular diagnosis or deficit; rather, it is a shared environment where recognition is given to difficult experiences but has an emphasis on the possibility that individuals can move forward with their life and belief that recovery is possible whilst offering opportunities to connect with others in a different way.

Partnerships are vital to the success of Recovery Colleges—in particular, partnerships between people who use services and mental health professionals. Recovery Colleges combine the strengths of individuals with lived experience (experts by experience) and professionals with experience. By working in partnership, Recovery Colleges are working towards a shared vision that is central to the working relationship and to the success of colleges. This is a stark contrast to traditional mental health services whereby the health professional is seen as the expert and service users are taken along a journey, one which often disempowers people and is rarely founded on hope. Being able move towards service users being experts in their own experiences and their ‘expertise’ is valued on the same level as clinical expertise means that true partnerships can be developed. In this way, individuals who access mental health services are able to drive and lead their own recovery, with support from mental health professionals.

Recovery Colleges use educational approaches to create opportunities for individuals to join a shared learning environment, which can support them on their recovery journey. Recovery Colleges are not therapeutic or intended to take the place of mental health treatments. Instead, colleges offer the opportunity for individuals to learn in a safe environment and develop their own skills to enable them to progress on their own recovery journey, having the freedom to choose the courses and workshops that they want to do, finding out who they are and seeing their strengths and abilities. Learners are offered the opportunity to take control, to make sense of and find meaning in what has happened to them and make decisions that affect their lives. The fundamental ethos of Recovery Colleges is that change is possible and colleges are the facilitators of change, creating opportunities for collaboration between professionals and the ‘lived’ expertise of individuals. There is a focus on choice, recovery and inclusivity. The inclusiveness of Recovery Colleges reinforces the principle that there is value in all experiences and there are opportunities to share and learn together.

Co-production

The first principle of Recovery Colleges is co-production. Recovery Colleges should aspire to collaborate between people who use services (expert by lived experience) and mental health professionals at all levels of Recovery College development, including course design, course delivery and quality assurance. It is suggested that increasing the collaborative relationship between healthcare professionals and ‘consumers’ enables services to be developed that truly meet the needs of consumers. Sherry Arnstein developed the Ladder of Citizen Participation which details the ways that people can get involved, ranging from non-participation activities such as therapy up to citizen power which includes developing partnerships. Recognizing the value that having lived
experience can bring to the development and creation of new ways of working enables the development of new services that really meet the needs of consumers. Working in this way appreciates that lived experience is equal to having experience through training. True coproduction is based on equality; no one is more important than anyone else, and this allows mutually beneficial relationships to develop and enables the collaboration to work together to create a shared vision to move forward.

The New Economics Foundation highlights that, whilst there is no agreed definition of co-production, there is a view that working in collaboration can change mainstream public services for the better and there is a growing emphasis on the importance of involving ‘consumers’ in planning and delivering services. Amongst Recovery Colleges, there seems to be more of a shared understanding that co-production is a partnership between experts by lived experience and healthcare professionals coming together to create a shared vision to create opportunities for individuals to realise their potential and move forward on their recovery journey. Co-production between an expert by experience and an expert through training enables the traditional concept of medical professionals being the expert in an individual’s experience to be challenged. An individual who has lived experience of mental distress is the only person who can be the expert in that experience. The importance of individuals being active participants in their own care has been highlighted by the U.K. Department of Health, in particular, service users being partners in their own care; thus establishing and maintaining effective partnerships are essential. Partnership has many advantages; most importantly, people’s experiences of using a service. It also enables flexibility in working practices and can improve effectiveness and outcomes for services.

Having the opportunity to be involved in co-production has been shown to have a positive impact on the self-esteem of experts by lived experience. This has been attributed to the opportunities created by having the prospect of exploring a new identity as a professional. This shift of recognizing the value of individual experience is a fundamental change within mental health services and is founded on the belief that all have something of value to offer. This is a paradigm shift from mental health professionals being at the top of the hierarchy to recognizing that lived experience is of equal value. The more experts by experience are involved in education about recovery, the more recovery-focused our mental health services will become, which can only be a positive thing as this can influence a real cultural change within our mental health services. Routine co-production of services to support recovery is the next step in developing recovery-focused services, so in many ways, Recovery Colleges are leading the way as being a living example of co-production in practice.

An important point to note is that relationships and partnerships cannot be forced or engineered. Genuine respect and belief that everyone has something of value to contribute is the foundation of true co-production and meaningful partnerships. Long-lasting relationships have to be cultivated, nurtured and developed in order to have a sustainable impact. It is not about always agreeing with each other, but it is about coming together with a shared objective to help facilitate a positive change, a change that empowers people and changes lives. Co-production is working in partnership to create a shared vision to work towards leading the way together.
Establishing true equity in relationships is about genuine respect, recognizing that all have valuable perspectives to offer, which enables a deeper, richer understanding of other people’s viewpoints to be developed. The collaborative group holds the power together, making decisions together with the interests of everyone central to decision-making. The positive impact that being seen as an equal has on an individual’s self-esteem and self-identity has been noted, and this suggests that collaborative working not only benefits the wider community but also has individual benefits for those involved.

The excerpt below is a service user’s experience of co-production in a Recovery College. The writer highlights the importance of being treated as an equal partner in the relationship with mental health professionals and the positive impact this has on their identity. There is recognition that being an expert by experience is valued as equal to being an expert through training. This influences their confidence to contribute and be involved.

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Co-Production Within a Recovery College: A Service User’s Experience

The introduction of Recovery Colleges, with its core value of co-production, has been central to living a more meaningful and satisfying life that has allowed me to regain a sense of hope and control with opportunities to return to work and rebuild my life. My role and identity as a service user relying on the system has been transformed and I’m now a facilitator, delivering co-produced recovery-focused sessions. A process that started from simply engaging with services to becoming involved in co-producing the very service I was using. Initially, my level of involvement with mental health services was confined to basic participatory levels, such being invited to consultations in order to provide feedback but with all the decision making and power still remaining in the hands of professionals.

However, when I was contacted by my supervisor, an important and integral part of my recovery pathway, asking me if I’d be interested in attending a recovery college meeting with her, I agreed to give it a go, but little did I realise at the time what a journey of self-discovery I was embarking on. For example I can recall someone who was involved in my care, turning up as a student at a recovery college session that I was delivering. Although feeling a little awkward at the start, once the session ended and I’d gone home and reflected on the experience, it dawned on me that something had truly changed within me. I suppose you could call it an epiphany. I was now more than just a service user; I was a valued person with knowledge and expertise to share with others. I was now living the talk and putting the policy of co-production into practice.
It’s been an empowering and liberating experience with its person-centred, strengths-based approach, using my lived experience and knowledge to improve services and outcomes for service users. Co-producing and co-delivering sessions with my supervisor where the decision making has been equally shared along with responsibilities on a reciprocal basis has been a transformative experience in terms of breaking down the barriers between ‘us’ and ‘them.’ Moving away from a therapeutic approach towards an educational pathway has enabled me to regain lost skills needed for work and life allowing me to self-manage my own care rather than leaving it solely in the hands of professionals, therefore allowing me to take back control of my life. Hope and opportunity has replaced despair allowing me to personally grow and reconnect with my community and society in a meaningful and satisfying way providing me with a sense of purpose, alongside a determination to stay well and move forward. It’s been an engaging and stimulating process that is still on-going whilst continually learning new things and increasing my knowledge. The opportunity to co-produce and co-facilitate sessions within the Trust’s recovery college has been an enabling and heuristic process. I have my life back and that’s just great.

It is clear that the offer of an opportunity was an important part of this service user's recovery journey. The pathway that the opportunity presented was unknown, but knowing that someone had the belief in them that they had something to contribute was a motivator to take that first step. The numerous benefits that this individual highlights mirror what a lot of the literature has found, including a positive sense of self, feeling valued, improved confidence and a sense of purpose.2, 3 The strength and positivity that comes through this piece of writing is reflected in experiences of learners who attend Recovery Colleges. The value of being able to create a shared learning environment where everyone is equal is hard to quantify, but it is something that all involved in Recovery Colleges appreciate, whether they are there as a learner, facilitator, part of the co-design or any combination of these.

Valuing Lived Experience

The value of lived experience is recognized in the development of Peer Support Worker (PSW) roles across both National Health Service teams and the voluntary sector;20 and PSWs are an integral part of the development and delivery of Recovery Colleges. “People in recovery have been providing informal support to one another for quite some time”21 and Recovery Colleges create an opportunity for peers to work collaboratively to shape a new way of working. The contribution of people with lived experiences has been described as “… challenging, inspirational, confrontational and supportive.”22 It can be a moving experience listening to an individual share their personal recovery journey, but it can also be a very rewarding experience for an individual to share their own story with others, being able to ‘use’ their mental health, positively reframe their experience that can inspire hope in others22 and also feel more confident and empowered about their own recovery.19,23,24 This reciprocal nature of story sharing is
powerful and much longer lasting. The emotions we experience when hearing an individual story of hope can be incredibly moving and humbling. Being able to develop a deeper understanding of the experiences of others can help us feel more hopeful about our own experiences.

Recovery Colleges create an environment where there are no labels and everyone is equal and free to share as much or as little as they wish. Being in a safe environment, one that is free from judgment allows individuals the freedom to explore their own experiences, learning from others and enabling everyone to recognize that they are an expert in their own experience. This is particularly important because service users often feel they have lost their identity or that they are defined by a diagnosis, so being able to drive change, be empowered to share their own story, positively reframe and to ‘use’ their experiences is immensely empowering for the individual.

Conclusion

Recovery Colleges are still in their infancy and there is much more research needed to build an evidence base about the effectiveness of Recovery Colleges. However, one thing is clear: co-production and collaboration between experts by lived experience and mental health professionals is the essential component in the development, sustainability and the legacy of Recovery Colleges. Starting from the point that everyone is equal helps establish better relationships and more meaningful partnerships. Recovery Colleges are founded on the key recovery principles of hope, opportunity and control; and these concepts are woven throughout every step of the college experience. The success of Recovery Colleges is founded in learner experiences. The messages people take away from attending Recovery College are vitally important in helping individuals move forward. The message of hope, that recovery is possible for everyone, the possibility of leading a meaningful life, one where everyone can contribute and where everyone is valued as an equal is the overriding message of Recovery Colleges.

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References


