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Leadership as Experts by Experience in Professional Education

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Abstract

Purpose: This paper shares the learning from a new course to explore and develop leadership by experts by experience involved in health and social care education provision, research and policy. Method: A Knowledge Café approach was used to provide opportunities for participants to explore and reflect together on shared experiences of what it means to be an expert by experience, and the extent to which the role can be understood in terms of grounded concepts of 'leadership'. Findings: The paper discusses how involvement as a service user emerged out of a personal drive to challenge and change appalling experiences of health and social care services. The paper goes on to illustrate this dynamic concept of leadership; the importance of networking with other users and carers, and, skills in enabling professionals to change. Argument and Conclusion: 'Professional leadership' is one of the domains of the UK Professional Capabilities Framework for social work defined as facilitated learning to include service users, carers and others involved.The call for a learning culture is not new and its application in complex practice and crisis points remains a current challenge. In contrast, the concept of Leadership discussed in this paper is grounded in experience and resonates with aspects of contemporary ethical, distributed and complex models of leadership but extends beyond organisations. Finally the paper raises the issue of learning opportunities available to experts by experience and the responsibilities for higher education and service providers to strengthen and support people in this complex role.

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1. Introduction

This paper discusses the learning from a new course designed for Experts by Experience involved in shaping health and social care to explore and develop leadership practice. We explain the term 'expert by experience' and outline the Knowledge café approach used. The concept of leadership practice that emerged is presented in terms of three dimensions:

  i. Loving into action

  ii. Networking together and across organisations

  iii. Two way listening and impact towards positive change

The analysis shows how experts by experience provided mutual support in situations of crisis and generated knowledge together. 'Professional leadership' in social work is defined as learning and development involving service users and carers (The College of Social Work, 2012) and we suggest in addition it refers to involvement in situations of crisis. The paper is based in England and we wish to link with and learn from initiatives elsewhere.

2. The Role of Experts by Experience

Service user involvement stems from social movements such as the disability and survivor movements who in the 1970s asserted the validity of their experience as the basis for social action needed for full civil liberties challenging 'expert' frameworks used in health and social care (Oliver 1990; Pilgrim 2005). Service user involvement in service development and professional education gained legal endorsement though distinctions between consumerist, therapeutic, and activist perspectives shape the scope and purpose of involvement and its limits (Noorani, 2013). New challenges emerge with neo liberal government through 'benevolent empowerment' overshadowing such espoused participatory principles of liberal democracy (McFalls and Pandolfi, 2014). We use the term 'expert by experience' to refer to roles beyond the immediate experience of being a service user or carer when that expertise is deployed in other situations, for example for contributing to student recruitment, teaching, research, policy consultation or service improvement. Fourteen experts by experience enrolled on this Continuing Professional Development course bringing a range of experience as carers and service users including disability and mental health.

3. The Knowledge Café Method

The course was designed by the authors whose roles include professional education, Knowledge Café facilitation and Expertise by Experience of psychiatry. The course aimed to understand and build on leadership practice that was initially defined as influence for change. We adopted a Knowledge Café participatory inquiry process designed to harness the energy of informal conversations around questions that matter to people as a creative way of innovating thinking and action (Brown 2001). Three workshops were provided over three months:

- ✓ Exploring and valuing our leadership by experience
- ✓ Deepening ways of thinking about leadership
- ✓ Developing our impact in health and social care

The first workshop introduced the approach and our initial questions: 'how do we understand 'leadership' as Experts by Experience? What do we need to develop and what support do we need when we are using ourselves and promoting the voices people using services? The introductory activities asked participants to share how they became Experts by Experience and explore what it meant to identify patterns and themes. In the month between the first and second workshop, participants were invited to map their journeys as experts by experience by creating 'rivers of

experience' (Percy-Smith and Walsh, 2006) and then together to identify times when they felt they had exercised 'leadership'. The programme was also responsive. We presented our interim reflections in a 'goldfish bowl' conversation for participants at the start of the second workshop. Activities were introduced for the final day to develop two themes identified: networking and two way listening. The final workshop included a review and presentation of CPD Certificates of Attendance. Draft reports produced in the café activities were circulated during the programme and confirmed subsequently and participants' consent for publication of quotations below was given.

4. Themes

4.1 Loving into action

Participants shared experiences of being expected to show deference to professionals who took decisions with 'godlike authority' either disregarding their feelings, viewing 'emotions' as part their 'problem' or patronising their being 'upset'. Sibling carers had childhood memories of the impact of that type of practice on their parents – 'made to feel the problem, disintegrated the family unit'. Involvement stemmed from personal experience and this was characterised in terms of love and deep regard. This intimate form of commitment drove the energy needed to raise challenges and bear influence. Becoming an expert by experience entailed tenacity, passion and courage to find ways to approach professionals, reminding service providers who the service was for:

- ✓ Love – keeping going, the source of energy, unconditional, passion, difference between experts by experience and professionals – professionals are not to be too 'friendly'
- ✓ Compassion – define this together
- ✓ Blame stops understanding and leads to alienation

Participants did not generally want love from the professional but the professional role needed to understand loving relationships in order to understand distress and the meaningfulness of what can otherwise be labelled 'challenging behaviour'; professionals need to recognise the link between love and distress.

Participants had become expert by experience aiming to improve the voice and experience of other service users and carers. The role differs from being involved as a service user or carer using support, but it continues to include that personal experience. Participants discussed knowledge gained, the increased self-value and sense of justice defining the role. 'Professional' relationships were viewed as bureaucratic rather than human. Managing this role meant entering the world of the professional on their terms:

- ✓ Templates and health and safety barriers
- ✓ Dignity, privacy, code of conduct, boundaries are professional
- ✓ Deprivation of love – never get a hug – should ask if someone wants a hug – safe hug
- ✓ Hug is human, different to a family hug, but important
- ✓ Consoling – no staff reaction, not sharing

As experts by experience they aimed to work with professionals to encourage change in their practices and their values to listen and recognise inadequate quality of services. Participants were using their lived experience to support other service users and carers highly aware of the difference of being isolated or connected. 'It's hell and heaven – hell of separation and self-rejection and heaven of connection' and this was not felt to stem from society but to what happens in services.

4.2 Networking between and across organisations

Networks were seen as central to leadership practice facilitating learning beginning with personal courage and openness to work out with others what needed to change. Supporting others meant listening and understanding their position. Networks enabled participants to sustain their focus and generate a clear purpose. Working alongside professionals entailed skills in both flexibility and tenacity and a sense of humour sometimes demanding considerable emotional labour:

Staying there, even though feeling unwelcome/uncomfortable and being sure of value of own experience

Importantly this meant 'developing as a leader from within a situation, not from personal inclination', but 'bringing people into what had been happening in secret and making things visible' by pulling resources together, knowledge, (such as law and who to talk to) skills and experience of others and self and forming a strategy. This concept of leadership was seen in contrast to formal leadership positions; experts by experience did not feel they were performing in solo but working in a context with others and with support. Networks were opportunities for reflexivity – the desire to be challenged in order to gain understanding, conveying confidence, authority and strength:

- ✓ Solidarity, good relationships, keeping the flame alive and sharing the load
- ✓ Sources of information and increasing 2 way understanding
- ✓ Understanding support for additional confidence to be able to express, to say what needs to be said and to put it on the table, honest – the authentic voice – that is when we can check it out with others – what you are saying is valid and that strengthens you
- ✓ Networks arise from adversity and lead to opportunities
- ✓ We are trying to survive and networks help us to survive the inequalities

As Beresford and Branfield (2006) found in their study of the impact of involvement, networking is not only a process or set of relationships, it is also a process of knowledge generation:

- ✓ When asked how user knowledge can make a more powerful impact to improve people's lives, service users highlight two closely interrelated issues. These are:
- ✓ 1 strengthening service-user networking at the individual and organizational levels; and
- ✓ 2 the promotion of effective user involvement by service users (Beresford and Branfeild 2006:443).

4.3 Two way listening and obtaining evaluation of impact

Listening to other service users and carers *and* listening to professionals entailed skills that are to be found in any general text on professional communication and were confidently expressed:

- ✓ Get ourselves out of the way, not to interrupt and be able to stay with the person
- ✓ Ask for clarification so person knows you are listening and reflect back what they say
- ✓ Paying attention – with our body
- ✓ Encouragement to the speaker
- ✓ Not to be analytical where it turns in to the 'facts' and more 'facts'
- ✓ Not to judge
- ✓ Listen to the baggage to get to the point
- ✓ Being honest about position as listener – availability recognise own conflict

'Listen to the baggage to get to the point' was a skill we observed during in the workshops where individuals sometimes spoke at length and gained conciseness as they were heard with encouragement. Listening enabled the development of understandings, shared insights and knowledge. That is not to say that all participants were fully heard or that there were no tensions, but time was palpably collectively gifted to fellow participants when they spoke. Facilitators kept to time throughout by dropping micro elements of the prepared activities which became unnecessary due to the spaces for conversation built into the knowledge café process.

Two-way listening meant knowing how far the contributions provided by the Experts by Experience had been followed through and acted on. A lack of evaluation of the impact and of process outcomes of involvement is recognised in the literature and is seen as necessary for meaningful involvement, to ensure quality and justify its funding (Robinson and Webber 2013). Here experts by experience wanted to know if *their* contributions are ignored or taken seriously for positive change. They also wanted to work out how *they* could obtain that information.

Participants told us that they found the workshops powerful:

- ✓ A very grounded discussion of leadership. Felt real and valuable. Human.
- ✓ Listening to how people became experts by experience despite some great adversity and the discussions

   around courage that it takes to use leadership
- ✓ Hearing, reading, viewing everyone's journey in leadership has been good. Listening to a variety of leadership is very inspiring, getting a heartfelt, passionate, commitment - a fix is a recharging of hope and joy.

5. Discussion

'Leadership' was initially discussed as the capacity to influence health and social care systems but then new meanings evolved throughout the Knowledge café process as a product of conversation and sharing of experiences. Leadership *between* experts by experience and other service users and carers became redefined as the basis for expertise, action and influence. Networking led to local and national support systems and knowledge being developed. The skillfulness participants showed in providing mutual support in and outside of the workshops, contrasted sharply with the examples of appalling practice described. But the significance given to networking and support by the experts by experience places emphasis on different priorities in health and social care. Service users generate knowledge through networks ''user networking and knowledge development are seen as closely linked and mutually dependent" (Beresford and Branfield, 2006:442). Such collective productions of knowledge differ strikingly from models of involvement that are limited to personal 'empowerment' (Robinson and Webber 2013). As Noorani (2013) suggests, 'experts by experience' pertains to the expertise gained through the experiences, becoming skilled and capable in self help developing self knowledge and authority together through sharing such experiences.

What are the implications or professional practice? 'Professional leadership' is one of the nine domains that span the career path of the Professional Capabilities Framework for social work in England defined as influence through learning and development to include service users and carers (Professional Capabilities Framework, The College of Social Work, 2012). In this study we heard how crisis situations had been a significant impetus for becoming an expert by experience and learned how important their role was in supporting others in critical situations. We therefore suggest that professional leadership includes the involvement of experts by experience in critical situations. Professional leadership can learn from the 'love to action' to awaken the courage needed to speak out, networking practices to swiftly mobilise support and two way listening for openness to reflexivity in a critical situation to develop a longer term view of well being together.

The leadership literature generally opens with the shift from a personal trait disembodied model of a 'leader' imparting vision and direction as being either heroic or horrific and the debates consider whether leadership is an Art or Science, a performance or an ethical practice. Looking at three models we can see some useful connections with the concept generated above. 'Leading Beautifully', (Ladkin, 2008) means that 'beauty', elegance, aesthetic are important especially when without positional power. This does not mean charisma but 'beautiful performance' and 'leading beautifully' – nourishing, inclusive, accepting, safe space, in the present, with pregnant potential based on subject knowledge and skill. The emphasis on feeling and inclusivity is affirmed. 'Distributed leadership' (Gronn, 2002) is collaborative, compassionate, generating knowledge as an emergent property of the group. This model also reflects the supporting networking generating knowledge. These two models do resonate with the ways that experts by experts work together and how they approach work with professionals in health and social care organisations, though 'models' can imply ideal conditions. Complexity leadership (Uhl-Bien et al., 2007) is a more obviously contextualised model advanced for fast moving innovation, drawing on complex adaptive systems models in science; temporary constellations, multiple hierarchies, learning & enabling, generative networks forming throughout the organisation. Importantly this model includes administration and management as part of 'learning our way out of new problems' without set 'rational' controls, boundaries, compartments etc. but by enabling of innovation. Complexity leadership is not either creativity or bureaucracy, but the 'entanglement' of these in contexts where they operate in connection or conflict. This picture of entanglement perhaps gets us nearer to the role of experts by experience and the challenges they face in their leadership practice, and resonates with our own leadership practice within the university to create the space and status for this course.

The concept developed here is distinctive in its 'user' and 'carer' perspective traversing organisations, whereas other models imply either no pre-existing organisation or leadership within and from inside the walls of the organisation. Positional power is not easily sidestepped or circumvented.

6. Concluding Thoughts

In this work we have explored understandings of what it means to be an expert by experience based on new insights and knowledge that has emerged through providing a space for Experts by Experience to articulate, share and reflect on their own experiences of leadership. In doing so we have explored key moments in the expert by experience role, which challenge assumptions about both the way in which health and social care services are provided, and relationships between service users and carers and professional providers. In particular by illustrating the importance of different priorities for experts by experience in the form of human dimensions to caring, but also the 'agency' of experts by experience which we have discussed here in terms of reanimated notions of leadership. We could reclaim the concept of 'resilience' to describe the sustained energy exercised by experts by experience and 'smart' networking practices in the face of adversity, embracing neo liberal ideas empowerment in the form of the 'entrepreneurial self'. However such interpretations discredit the fundamental essence of what it means to be an expert by experience that emerged in this work, focusing on compassion, networking and time to listen and value. Leadership practice by exerts by experience involve risks both to the integrity of the individual and to others that matter, and such leadership may become a struggle for survival.

References

Beresford, P. and Branfield, F. (2006). Developing Inclusive Partnerships: user-defined outcomes, networking and knowledge − a case study, *Health & Social Care in the Community*, 14, (5), pp 436–444.

Brown, J. (2002).The World café: Living knowledge through conversations that matter, *The Systems Thinker*, *Vol,* 12. 5 pp.1-5.

Gronn, P. Distributed Leadership as unit of analysis *The Leadership Quarterly*, 13, pp423-451.

Ladkin, D. (2008).Leading Beautifully: How mastery, congruence and purpose create the aesthetic of embodied leadership practice, *The Leadership Quarterly, 19*, pp31-41.

McFalls, L. and Pandolfi, M. , (2014). Parrhesia and Therapeusis: Foucault on and in the World of Contemporary Neoliberalism in ed. J. Faubion , *Foucault Now,* Polity: Cambridge, pp168-188.

Noorani, T., (2013). Service User Involvement, Authority and the 'Expert by Experience' in Mental Health, *Journal of Political Power*, *Vol. 6*, No1, 49-68.

Oliver M. 1990 *The Politics of Disablement,* Basingstoke: MacMillan.

Percy-Smith, B. and Walsh, D. (2006). *Improving services for Children and Families: Listening and Learning, Report from a systemic action inquiry evaluation process.* Northampton: Children's Fund Northamptonshire/ SOLAR

Pilgrim, D. (2005). Protest and co-option – the voice of mental health service users. In A. Bell and P. Lindley eds. *Beyond the water towers: the unfinished revolution in mental health services 1985-2005*. London: The Sainsbury Centre for Mental Health, pp17-26.

Robinson, K. and Webber, M.,(2013). Models and Effectiveness of Service User and Carer Involvement in Social Work Education: A Literature Review, *British Journal of Social Work*, *43*, 925-944.

The College of Social Work, (2012).Professional Capabilities Framework, , Accessed 10.9.14 http://www.tcsw.org.uk/pcf.aspx

Uhl-Bien, M., Marion, R and McKelvey, B.(2007). Complexity Leadership Theory: Shifting leadership from the industrial age to the knowledge era, *The Leadership Quarterly*, *18*, 298-318.