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Allyship or coalition? Creating lived experience roles in academia and why we are not quite there yet.

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Abstract

Allyship is regarded as an important role in the academic setting to support the inclusion of people with Lived Experience (LE) of mental health and addiction challenges. Understanding the context within which the allies in academia work requires further scrutiny to ensure power sharing. Mental health academics have created a body of published literature on LE in academia, presenting both the successes and barriers to authentic allyship. This narrative provides a dialogue between a person in an LE role in a university setting and a nursing academic regarding their experiences of allyship. These reflections present the potential challenges the LE role and their academic ally can face in establishing and sustaining these roles. The structures within the university setting that impact on the success or not of the role of ally are also considered. This narrative further contributes to the contested role of allies and offers a closer analysis of allyship and the power dynamics in play. We conclude by offering the notion of coalition as an alternative to allyship and an alternative approach to the success of the LE roles in academic institutions.

Key words

Allyship; coalition; curriculum; lived experience; mental health; narrative; racism; sanism; tokenism

Introduction

This narrative presents a dialogue between both authors, documenting their personal reflections on the role that the LE in academia can play in the future preparation of registered health professionals, particularly from a mental health and addiction perspective. The key messages are two-fold; firstly, a level of support is required to create successful partnerships between the person with LE in the academic setting and their other colleagues in the university. Secondly, to understand if the current notion of allyship helps or hinders the success of this partnership. The narrative concludes with reflections on what makes this partnership work, the benefits for

academic staff, and the consequences for curriculum activities. The following dialogue is represented by two voices: the LE role, Debra, and the nurse academic, Helen.

Debra: I am a person with lived experience (LE) and have been teaching in both health and academic settings here in Aotearoa, New Zealand, and internationally for the last 24 years. In those early years, as LE, we didn't generally have substantive roles in academia. Therefore, we were invited to speak as guest lecturers, usually on an already established lesson plan, often based on the lecturer's perspective and assumptions about the person's diagnosis or their formulation of what they think was wrong with the person. As people who use services, people with LE want future practitioners to be confident to speak up and challenge the status quo in current clinical environments, and the classroom is one place to start. However, it is crucial to consider the broader aspects of LE roles being employed in academia and progress with caution, as they have to be safe places to share our experiences.

Helen: I have an academic role and was part of setting up the new school of nursing at the University of Auckland in 2001. At that time, I was able to employ Debra as one of the few roles of others with LE in a university setting in Aotearoa. Together, we developed Debra's role as the subject-matter expert, who is *qualified* by her experience, for the content of the teaching rather than the standard academic role description with associated expectations of administrative functions, etc.

Background to allyship

The role of LE is now a highly regarded concept, and though scholars have argued vociferously for the inclusion of these roles in academia (Byrne et al., 2016; Byrne et al., 2013; Byrne et al., 2018; Happell et al., 2023; Happell et al., 2018; Schneebeli et al., 2010), their implementation has faced many challenges. We argue that the concepts of participation and tokenism need to be interrogated before recommendations can be made about how the role of LE in health education can be achieved. Our experiences of creating this LE-academic alliance over the years in the university setting have reported quantifiable benefits (Schneebeli et al., 2010), such as students increased effective interprofessional working and increased knowledge and skill acquisition through these real learning opportunities. The LE role also benefits the students who may share their own lived experience of mental distress with others, which will shape their values as future clinicians. Nevertheless, we caution that safe partnerships between LE roles and academic staff are only achievable with clear communication about the expectations and clarity of the role for these valued voices of experience.

Debra: I agree that having LE roles involved can directly impact health practitioners' attitudes and practice through the different perspectives of the person with lived experience. However, the lack of dedicated funding for these LE positions is also a barrier to those academics who wish to employ substantive roles. Seeking resources to support these LE roles can work if the academics become allies to each other in seeking and negotiating LE employment and appropriate remuneration, other than gift vouchers, for example.

Helen: There is a body of work by scholars, such as the recent work by Happell et al. (2023), who argued that academic staff can be allies for their LE partners; for example, in the coproduction of research, the authors report the barriers, such as hierarchies of power in the academic institutions, lack of support or funding to remunerate the person, and the tokenism

and associated negative stigma and discrimination that LE colleagues have experienced in these settings.

Debra: If allyship is a crucial concept and role, we must identify these barriers and create opportunities to establish, implement and sustain these LE positions. However, we must be clearer about the terminology. For example, the LE role in research is essential. However, 'co-production', 'co-creation' and 'co-design' need to be genuine partnerships; for example, funding for research may be hampered by conformity in the academic setting, e.g. who gets the funding, who picks the topic to be researched. As LE, it can feel like we are the 'optional extra' rather than the imperative in the research team. The role of the ally must not 'co-produce' the LE role without the LE's involvement in 'co-creating' the role from the LE perspective.

Helen: Identifying the role of people with LE has been fraught, particularly in academia. In my experience - whilst efforts to find titles that reflect the persons' value and contribution - nomenclatures such as patient, consumer, service user, and expert-by-experience can risk further stigmatising and devaluing of these roles, resulting in exclusion from the academy. Therefore, we need to scrutinise the term allyship to avoid another process of unwittingly stigmatising LE roles further within the education setting.

Debra: I agree that careful scrutiny of the term ally will be important for these alliances, including identifying issues of power, control and tokenism that undermine the inclusion of these valued voices; we need not to perpetuate a "fantasy" of allyship (Moten, 2017, p. 280), and risk the lived experience being 'othered'. So, we need to be careful of what we wish for in employing LE academics because it will require allies in the faculty to have hard conversations within their faculty team. For example, of what and whose knowledge is valued? What changes are required for experiential learning rather than prescribed 'textbook' learning? Health professionals of the future need to learn the key ingredients in supporting a person's recovery – the need to feel connected - which may require an emotional response from the practitioner. I note that in academia, the term 'soft skills' is used regularly; this term can be interpreted as an emotional response that may imply that the professional is now 'over-involved' or has blurred the boundaries of the therapeutic relationship, therefore diminishing the nurturing of the spirit of the person. It becomes a type of devaluing attributed to the feminisation of skills. I think some health professionals miss out on not being able to share 'emotional' responses with service users.

Helen: I note that you have had firsthand experience in your career of 'othering' when you were previously involved in clinical teaching. The state of otherness is a common experience and not a static state of being. Rather, othering is an ongoing process perpetuated by how the dominant group treats those perceived as different due to the possible threat to the privileged insiders (Hamer et al., 2014). These are alienating strategies and are evident in a range of institutional structures, including universities; therefore, it is a common experience resulting in the person with LE being feared and held in low esteem.

Debra: I suggest that 'otherness' and being 'othered', rather than being disempowering, can also be defined as 'an-other' – possessing an alternative form of expertise and power. If a university is seen as having academic freedom and acting as the critic and conscience of society (Grant, 2019), this creates an environment where we can share our informed opinions. It also allows us to validate our lived experiences as valuable forms of education and knowledge. At the same time, we can reclaim our role in society through our status within the

academy. Therefore, I see all LE roles in the academy as consciousness-raising; that is, by raising our experience as LE to an intellectual level, we can provide nursing education at its most sacred and revered. The result of embedding a more humanist approach could contribute to creating a community of acceptance, whereby the academy itself becomes another form of activism and provides the consciousness-raising of health professionals that we prepare for future practice.

Creating Allyship

Helen: Therefore, academic allies who wish to promote LE roles must understand the journey that people with LE have undertaken to overcome othering and surviving oppression. Understanding this will bring valuable learning from the LE academic and, at the same time, illuminate the parallel of the exclusionary practices in academic settings that impact both the LE role and the academics. The outcome is that academics can learn from the LE experience and consequently do their own personal and professional work not to perpetuate the oppression, racism and sanist attitudes (irrational fear of the mentally ill) that directly stigmatise and discriminate against people with LE.

Debra: Well, in order to eliminate oppression, we have to de-medicalise our approaches to these partnerships and change the paradigm. The work that academics need to do, and of course, this extends to the clinical setting, involves understanding how these structures of power and control within institutions impact their desire to be true allies to substantiate the equal partnership within both our roles. We need to look for any parallels that help us to understand why there is a cycle, often unwittingly, of sometimes diminishing the success of the LE roles. I refer to Saad's (2020) critique of the architecture of racism as a viable way to identify the barriers and enablers that academic colleagues may need to be aware of to take on the true role of ally. If we can work together to create culturally safe and respectful partnerships, we can also model this same partnership of the LE-clinician alliance to students. The art and craft of being a health professional in the future will provide the most powerful 'medicine' of supporting users of services by developing their own understanding of how stigma and discrimination in society are, literally, crazy making.

Helen: Our work in the arena of antiracism in Aotearoa, New Zealand (Came et al., 2020), may offer a parallel process to understand how the role of allies can successfully support LE in the academy. A connection between allyship and oppression has been recently identified in a study by Happell et al. (2023). The authors found that the nurse allies interviewed reported difficulties in their relationships with LE colleagues. This finding is based on the interplay between the LE person and the academic ally, the latter now representing a member of the nursing profession with whom people with LE had negative experiences whilst in the care of nurses. For example, one ally participant likened their relationship to a form of oppression, and another ally recounted the triggering for both parties, leading to the ally recalling a similar negative experience as a white person working with Indigenous populations. It was clear that in these examples, the forces of colonisation and racism can trigger negative experiences and associated strong emotions for both parties.

Re-Thinking the Role of Allyship

Helen: Allyship can broadly be defined as the active, consistent, and challenging practice of unlearning and re-evaluating, in which a person of privilege seeks to work in solidarity with a marginalised group (Bishop, 2023; Max, 2005; McKenzie, 2014; PeerNetBC., 2018). Therefore, allyship is not an identity; instead, it is a lifelong process of building relationships based on trust, consistency, and accountability with marginalised individuals or groups. Further, Sumerau et al. (2020), warn that the construct of allyship can perpetuate social inequality by bringing a focus on the individual rather than the structural inequalities. Hence, it will require the ally to both contest and engage in concrete efforts to challenge the systems of oppression. Importantly, as Dabiri (2021) warns, the work and efforts to become an ally must be genuine and recognised by the people we seek to ally ourselves with.

Debra: I agree with Dabiri, who argues that unless this deeper work is undertaken, then allyship only serves at the surface level to platform the ally; it makes a statement but does not go beneath the surface, nor does it break away from the systems of power that oppress. So, I am concerned that it is symbolic rather than substantive allyship. Unless attention is paid to the power and oppression in organisations, then, as the allies in Happell et al.'s (2023) study reported, it can lead to the allies feeling victimised and, at a deeper level – as a direct challenge to their own power and privilege. If we apply the lens of racism and oppression, then we can see the paradox within allyship and the imbalance of power. If academics can develop their own cultural competence and cultural humility (Hamer et al., 2022) to confront their prejudices and practices, for example, when working with Indigenous populations, then working alongside the LE role can help academics develop a similar type of humility to work alongside people with lived experience of mental health challenges.

It will require the academic's openness to learning and the required un-learning, which is uncomfortable. That may be part of the partnership; however, it does not guarantee change. Saad (2020) quotes Thomas' (2017) notion of optical allyship - it looks good but is not embedded. Phillips (2020) asserts that allyship is based on genuine partnership whereby allies commit to supporting social justice and promoting the rights of the marginalised to overturn inequities. Allies establish authentic relationships to support but not lead non-dominant groups. I understand this to mean that the ally's desire is not to be seen as racist, or more commonly in my setting, sanist, so they became a conscientious supporter of my role whilst managing their perceived (and unexpected) threat to their comfort zone.

Performing Allyship

Helen: Performing genuine partnership as allies then is essential, as well as being familiar with the discomfort this may bring, such as not wishing to say or do the wrong thing. Therefore, we must listen and take guidance from the LE role to normalise any fragility we may feel as nurses. Kidd et al. (2020) remind us that consumers of health services, as well as health practitioners, experience racism, power and prejudice as an ideology of White supremacy, and the valuing of White culture underpins their hierarchical ranking as ethnic groups. In Aotearoa, New Zealand, health professionals are guided by the Tiriti o Waitangi [the Treaty], a founding document that provides the specific competencies and clinical practice to work within a bi-cultural approach (Papps & Ramsden, 1996). As health professionals, we must provide cultural safety and humility to create equitable health care and wellbeing for Māori. So, we are well

prepared to take this guidance and apply some of these principles to create true power-sharing between LE roles and academics, too.

Debra: Otherness is another form of expertise; therefore, LE roles bring the unique experience of the journey of consciousness-raising of the injustices of oppression and the power and privilege that operate in the master-slave dynamic. Bringing our narratives into the classroom as an oppressed group helps to reclaim the negative labels that prevent LE from remaining in the closet about the lived experience. However, in the past, I have experienced our powerful stories of distress being diminished by the audiences to a form of theatre rather than for education. However, allies must understand how the LE positions will create change from the inside and impact their roles.

Helen: We now have a growing body of LE wisdom and a larger LE workforce in Aotearoa, New Zealand. We have both been on the research team to investigate the future curriculum for health professionals (Shaw et al., 2024; Shaw & Heap, 2022). Our qualitative data from both health professionals and members of the public reports overwhelming support for having people with lived experiences of a range of health challenges be actively involved in academic classrooms and present in clinical settings to inform future health practitioners. This consistent finding shows the immense support of having the LE voice involved in the academic preparation of all health professionals, so we must understand allyship and what is required to support future LE academic roles.

Debra: LE roles must pave the way in the academy by raising consciousness again. Therefore, academic health professionals should claim their own power to subvert the academic system and support LE rights so the roles can experience the same peer esteem. You can unlearn one's prejudice, and those willing in the academy have already shown that they have opened a space for LE to create a body of knowledge that will challenge oppression. It will be important for academics to critique the definition of their role as an ally and the privilege that this brings. The university will have multiple intersecting systems of privilege and oppression; therefore, partners - LE and allies - will need to operate at both the micro and macro levels and use both partners' privileges to create affirming educational experiences and spaces.

Allyship or Coalition?

Helen: Saad (2020) further warns that dismantling the system of privileged knowledge in academia and curricula will induce discomfort in the advantaged owners of the educational content. So, university leaders will need to make efforts to destigmatise their organisations by requiring academic staff to undertake the deeper work of anti-oppression. However, we are reminded that the foundational principle is—do not expect to be taught or shown—by those who have less power than you, so academics must do the work.

Debra: It feels like we are doing anti-oppression work, but is it allyship? However, unless we unpack the power dynamics, I feel obliged to be your (often silent) partner if I do not feel safe. Can I trust that as my ally, you will support me in my role, or will I be constrained in what I have to say and thus become silenced? It's the little things, the micro-aggressions, that you may not see. Can I trust you to know that this is happening to me? Could we see this as a working relationship, like colleagues, to generate the energy for the role by being connected by the heart to achieve what LE roles wish for? I note, however, that allies need support, too, particularly

when their academic institution does not fully embrace the initiatives to employ LE positions (Happell et al., 2022).

Helen: So being a 'good' person in our eagerness to perform allyship can be perceived as patronising, inducing guilt and benevolence, increasing the LE roles 'victim' identity, and reifying the power imbalance. To avoid this, let's consider the difference between allyship and coalition. Dabiri (2021) helps us make sense of this subtle difference between the two; she argues that as allies, we are unwittingly perpetuating charity at the expense of solidarity and, therefore, offers the alternative notion of coalition-building. Coalition requires us to identify our shared interests, destabilise the status quo, and reduce the risk of segregation of interest groups that paradoxically reinforce difference – and therefore avoid the fantasy of allyship. However, Coalition is mutuality based on a shared, reciprocal approach to discussing systemic change and not individual actions alone. This helps us understand the previously mentioned trauma and distress of the academic allies, especially when they, too, may feel they are working alone and unsupported when they partner with LE roles.

Debra: Yes, and consequently, for LE roles to survive, systemic changes need to occur at the deeper level of the academic system with a focus on the curriculum and pedagogy – how adults learn and how the institution, if it is based on social justice, shapes the experiences of both teachers and students to develop a moral and political practice. Teaching is more than a 'method' and instead promotes the interrogation of societal values, norms, and power structures. Students can then reflect and understand how their personal history and aspirations for the future shape their sense of self in the current moment. This is similar to clinical work, where students learn the art of 'being with' rather than 'doing to' when collaborating with the people they serve. This is where the synergy of teaching and learning occurs in both the classroom and clinical settings. We know that including LE narratives will break down the us/them binary and bring recognition of how the marginalised are excluded from the knowledge-construction process and whose knowledge has more privilege than others. McKendry and McKenna (2020) describe this as the hidden curriculum.

Allyship and the Curriculum

Helen: So, including the narratives and subjectivities of the LE is an essential part of deconstructing the us/them binary and embedding the LE specialist body of knowledge. However, this requires the exposure of the hidden curriculum, such as racism and sanism. Church (2013), a leader in the MAD studies and lived experience academic movement, reports a gap between the rhetoric and actuality of practice, which is not deeply explored and therefore remains 'hidden'. Daya (2022) further adds that this notion can be understood as epistemic injustice that continues to oppress and silence the voices of LE as a minority group within academic settings, thus rendering the LE wisdom as "fugitive" knowledge (Harney & Moten, 2013, p. 5) which is transitory, rather than deeply rooted within a curriculum.

Debra: LE knowledge is the common sense that belongs to people with LE and is derived from our heritage. It is the knowledge that is practical and empowering. It has allowed me to survive, interpret, and create a new body of knowledge to bring to the curriculum. As health professionals, you have decades of writing from many theorists who have pioneered the professional body of knowledge you may now take for granted. The LE roles can work alongside your academic role to explore, research and manage the tensions and paradoxes that

emerge from our multiple experiences. Only then can we share power and, as activists, legitimise our marginalised knowledge that must remain outside the scientific paradigm, which has dominated for so long. It is okay to be subversive, and paradoxically, it may be that LE roles need to retain the role of a 'fugitive' and an outsider – but on our own terms. Being a fugitive can have positive connotations; for example, all public universities in Aotearoa, New Zealand, have a responsibility to serve the public good and have a legal obligation to take up a role as critic and conscience of society. I believe that including LE's substantive and equal roles will support future health professionals' preparation to provide a fairer and more just health system.

Helen: We spoke before about the risk that working together as LE and nurse academic – and based on Happel's (2023) finding – creates distress for the LE partner due to the institutional trauma that they experienced in their care by mental health professionals. Therefore, it seems that universities are not immune to these dynamics, as well as the racism, sexism, ableism, and sanism that LE roles can encounter in both health and university settings (Johnson, 2020).

Procknow (2023), has provided a critical analysis of the inclusion of Mad Studies in academia and reports that, amongst other impacts, its introduction has highlighted how such studies have revealed the degree of sanism in the university, e.g. the continued surveillance of mad bodies/minds and mad disclosures, the threat to educational policy, and the subsequent higher degree of risk to the wellbeing of "mad" lecturers (p. 93). Hence, Procknow argues that "steadfast allyship" (p. 88) by educators who identify as being "mad-positive" (Church, 2013, 2015) are required to speak back to sanism through the development of critical praxis and mad-positive allyship. However, as nurse academics, we can also be triggered by our recollections of the injustices that we witnessed within the psychiatric system, resulting in our own internalised shame which can trigger our own trauma associated with these experiences. It is important that this trauma is associated with the institutional structures of power and control within the university that privilege some and marginalise others rather than it being the 'flawed' or 'damaged' professional self.

Debra: Likewise, we also need to create equitable LE role descriptions and remuneration that do not continue the othering of people who are employed for their difference and would again look to steadfast allyship to reduce sanism and the micro and macro aggressions that the LE role can encounter. Creating a safe environment requires that all academic staff do their personal work identifying their blind spots and prejudices; this is not a failure of the individual. Rather, it is the institutional power and control that sets the culture in the workplace. Identifying this is the first step in reconciling the differences that it perpetuates. Academic staff need to be allies for each other, and as colleagues, the LE roles can support staff to take the leadership in creating the environment to support our roles: this is a coalition rather than allyship (Dabiri, 2020). The role of LE in academia will directly challenge academics and students to consider their roles in influencing a health system that oppresses all. LE roles and academic partners actively contribute to developing deeper-level curricula theory that underpins current programmes. However, be careful what you wish for as an ally, as according to Happell, Scholz, Gordon et al. (2018), it can be a rocky journey, and the reason why they "don't think we have quite got there yet".

Conclusion

Health professionals are bound by moral and ethical mandates, requiring the workforce to resist and deconstruct oppression in all its forms. Incorporating critical race theory (Kidd et al., 2020) and how that plays out in our relationships with LE roles means that this is now the work of social justice and health equity. Our contribution as academics is to uphold the rights of the people we serve (United Nations, 2006); only then can we truly be formidable (and steadfast) allies for LE roles with equal power and peer esteem. Further, we echo the guidance of Nixon (2019) and McKenzie (2014), who concretise authentic allyship as a relationship between those in powerful and privileged positions and a person from an oppressed group. This requires the practice of critical allyship - an active, consistent, and arduous practice of unlearning and re-evaluating this working partnership through authentic relationships. Being an academic ally requires a strong sense of social justice to dismantle an oppressive system; the ally, as the privileged person, therefore requires the courage to do so by consistently identifying the inequity and inequality within the system they work in and to defend, protect and work in solidarity with the person who represents the (many) oppressed groups. Trusting each other as partners and coalescing to understand what allyship means in this context will provide the opportunity to discover the answers together.

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