



“ A real, but old urgency...”

Georgina Cockburn is a PhD student at The Centre for Dance Research at Coventry University centred on People Dancing’s Live Well and Dance with Parkinson’s programme. We join her on her research journey around the UK contemplating the importance of capturing individuals’ lived experience in the programme itself and the wider world.



All images: Summer School 2022 Finding Flow.
Photos: Rachel Cherry.

We ourselves – eyes, bodies, feet and all – are at work in the field of play. And this is manifestly so, that is, it is reflected in the very manner in which anything ever shows up in experience. (1)

Ensnared in the basement (ok, lower ground floor) of De Montfort University, Leicester, I was sifting through notes and documents collected from People Dancing's (PD) 35+ year history, which is held in an archive special collection in the library. My neck was stiff and the tips of my fingers were starting to tingle, registering the cold. I had just drafted material on the methodology I was to use in a collaborative PhD I am working on at The Centre for Dance Research (C-DaRE) at Coventry University and was beginning the archival research element. I am focusing on People Dancing (PD)'s Live Well & Dance *with Parkinson's* programme and have C-DaRE Director Professor Sarah Whatley and the Programme Director Yaël Owen-McKenna on my supervision team (2).

At each step of the research, I have felt wonderfully aware of being within a rich network of existing partnerships and collaboration, between C-DaRE and People Dancing. My exploration into methodology had inevitably engaged with dance writing's strong tradition of using phenomenological approaches to criticism and research. I have thought a lot about how my whole self might be drawn into an exercise of understanding the phenomenon within the Live Well and Dance programme. I have thought about my curiosity and how it occasionally bordered on nosiness and that this constituted 'fallenness' as a researcher. I thought about how the wrong breakfast might produce a kind of restlessness in me that might make me inclined to try to map things out before being given a whole picture. I considered the disappointing and joyful reality

of a person doing research – underslept, over-caffeinated, ego-inflated/deflated, bunged-up with a dust allergy. This would all bear down, in some way, on the theory that generated 'itself' from my notes. How utterly interesting...and annoying!!! This, the embodied, reflexive role of the researcher, deepened my understanding of the importance of valuing and attempting to record the embodied experience of the 'subjects' of my research and it has renewed my sense that there is a real, but old, urgency in this.

The Live well & Dance programme maps out like vascular networks, moving out from a central individual (usually), to where another hub is. It seems that sometimes this hub looks like 'need' and sometimes it looks like 'resource', but usually both. The individual aspect to it all is partly where the research lies. What is the 'lived experience' of the individual? How can the individual have a meaningful stake in the research? And what artistic impetus does each person bring, as the group moves, aiming to improve the felt, daily experience of each individual in the room?

People Dancing is nurturing a programme that is discovering its own way. In Birmingham, Leicester/shire, Bristol, Cumbria, Newcastle and Manchester, it is attempting to gently support the programme as it finds its feet in each distinct place. In so doing, the programme is growing to yield some interesting information about inclusion, place, individuals, evidence and ownership.

The management/support of the programme looks not dissimilar to the overall management of People Dancing as an organisation; like the stewarding of 'ecologies of culture' and is spoken about in such terms (3).

Each 'hub' is managed by an Area Creative Coordinator (ACC). This role is responsible for shaping provision in their area, some ACCs are also delivering practically as Dance Teaching Artists >>





All images: NE Live Well & Dance *with Parkinson's* Performance Collective. Photos: Alice Elizabeth Photography.

(DTAs) for their region. Each ACC has suggested an awareness of having an individual/regional approach: comments include “...that’s what it looks like here”, “...this area is a bit different”, “...because of the distance she needs to cover”.

The ACC in North Cumbria, Susie Tate, is explicitly encouraging co-ownership through co-creation, involving her Live Well & Dance group in proposed activity that asks for our different experiences of the natural world to be fed into movement work. She aims for this to support a ‘handing over’, that recognises the expertise of those with lived experience of Parkinson’s. This, in turn, has aims to allow people to reclaim their wholeness in the light of a Parkinson’s diagnosis, to reimagine their agency perhaps. All of this is so intimately linked to logistics, and to enabling access both physical and attitudinal – and for this group, neatly, the way to reconnect with self and increase purpose is through trees, plants, roots – the Cumbrian landscape: “It’s focused on [...] the day trip. The group has come up with loads of places they either have been to and love or haven’t been to in many years or would like to go to.” (4)

The discourse and development of community dance in the UK, steered in part by People Dancing, has enabled ‘Dance for Parkinson’s’ (5) to be operating from a person-centred and inclusive foundation. Professor Sara Houston, who has pioneered research in this area, (6) refers to the community dance movement and reminds us of the underpinnings; the belief that anyone can dance (7). This bedrock ushers in a valuing

of the individual’s creativity and artistic input that resists the paradigms originally attributed to chronic illness and disability – the sick role and the personal tragedy narrative. It resists the ‘moral economy surrounding health and illness’ (8), and the medical model of disability. Dance practice involving disabled people and its attendant theory has taught us much about the discrimination that dominant ideas surrounding aesthetics and excellence brought to dance (see Adam Benjamin, Ann Cooper Albright and Sarah Whatley) and facilitated the development of a rights-based approach to inclusion in community dance. I am interested in asking how far co-creative endeavours within the Live Well & Dance programme might go towards dismantling the sick role, and whether this dismantling resonates through the partnerships with health professionals and providers to influence systemic decisions and policy. Too ambitious? Maybe, but maybe not...

Provision for the Bristol hub of the programme has snaked down to Wells, where a participant living with Parkinson’s whose career had been in the arts, found space and extra funding to host a group near the cathedral town. I have the privilege this term of joining class each Thursday. The group know each other well. Whether it be due to diagnosis, design, desire or serendipity, ACCs and DTAs across the programme talk of the Live Well & Dance groups as being especially cohesive in some way, more like a company than a class. This reported aspect of the class relates directly, in my mind, to the aim of the programme



to have people with lived experience of Parkinson's at every level of decision making and activity. Remembering the initial conversations that led to the programme in its current form, one ACC recalls that the impetus came partly from one individual with lived experience advocating for activity in his area. The 'feel' of the group in Wells is governed by this shared and localised leadership. Interesting to me, is not only the model that has established itself, lightly and organically, within the programme, foregrounded by dance involving disabled people, but also, what new insights into inclusion these models might be offering? What are the specific barriers in this specific context?

One scent that I was following in the De Montfort Archives that day was Dance, Health and Wellbeing within People Dancing, which has been a branch of People Dancing's work for some time. The shift from 'delivering to' to 'working with' is clearly evident, as is the endless work of trying to ethically 'evidence' the work of dance; to translate it into something that satisfies the systemic need for productivity, but that somehow communicates a tacit knowledge that dance is really, powerfully, good for you.

Dance for Parkinson's produces great evidence, there's lots of it and it's really positive. But...if we fund and prescribe dance provision that is designed around sustaining this output, might we lose what is uniquely gifted through dance? When I speak of urgency, I refer to the work of listening and experiencing what really matters to those living with chronic, life altering, long-term illness and responding and providing in accordance to this - not in accordance to what might further allow neoliberal ideas to strengthen the imperative for the ill person to manage and treat their illness, at low or no cost to the state.

References

1. Nöe, 2012: 3 Nöe, A. (2012). Varieties of presence, Harvard University Press.
2. C-DaRE Director, Professor Sarah Whatley and People Dancing's Live Well and Dance *with Parkinson's* Programme Director, Yaël Owen-McKenna. The PhD is an Arts and Humanities Research Council (AHRC) Midlands4Cities Collaborative Doctoral Award.
3. Holden, J. (2015), The ecology of culture.
4. Quote from an interview with ACC Cumbria (North), Susie Tate.
5. 'Dance for Parkinson's' originally termed such as work grew out of the Mark Morris Dance Group's Dance for PD® programme. The Live Well & Dance *with Parkinson's* programme has consciously chosen to use 'with'.
6. Research by Professor Sara Houston, Houston, S. (2019), *Dancing with Parkinson's*, Intellect Books.
7. (35: 2019) as above, Houston, S. (169: 2005), Participation in community dance: A road to empowerment and transformation?, *New Theatre Quarterly*, 21(2), 166-177.
8. Moral economy of health and illness (Zick Varul 2: 2010). Talcott Parsons, the sick role and chronic illness, *Body & Society*, 16(2), 72-94.

Info

Live Well and Dance *with Parkinson's* programme:
www.peopledancing.org.uk and
 Centre for Dance Research: www.coventry.ac.uk