

Involving people with lived experience in physiotherapy education – Research report three: Developing equal partnerships.

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Introduction

This report is the third in a series of research reports (see reports [one](#) and [two](#)) critically reflecting on the involvement of people with lived experience in a UK based physiotherapy degree programme. The goal of all three reports has been to challenge the lack of empirical evidence base for involvement in physiotherapy education. Part one focused on reflecting together to enhance teaching outcomes (Jury, Mohan and Hughes 2022) and part two focused on Harnessing the expertise of people with lived experience (Easterbrook, Blackman, Collins and Hughes 2022). In part three, we focus on the nature of the relationship between the academic and the person with lived experience and the benefits of genuine and meaningful collaboration. In keeping with our partnership approach of bringing people with lived experience and academics together to work as equal partners, this case report has been co-designed and co-authored.

The nature of relationships between educators and people with lived experiences is well documented in literature which explores the involvement of people with lived experience in health and social care education. Issues of power, control and influence and the nature of equal and meaningful partnerships are often explored. Arnstein's (1969) ladder of involvement and Tew et al. (2004) ladder of involvement framework, for example, seek to differentiate between different types and levels of involvement with meaningful involvement only being achieved when power is delegated (Arnstein, 1969; Tew et al., 2004; Webber & Robinson, 2012). This report explores the power differences between the person with lived experience and the academic. The report follows similar trajectories to Arnstein's (1969) ladder of involvement and Tew et al.'s (2004) ladder of involvement framework. This collaboration has grown out of Sophie's sense of her role within the PIER partnership and ongoing development of the relationship with the lecturer who is a physiotherapist. This has enabled the balance of power to become equal. Underpinning principles of trust and relationship building are also identified as important pre-requisites for meaningful involvement and for people with lived experience to feel valued and heard within the classroom setting (McCutcheon and Gormley 2014, Warren et al. 2017, Reith-Hall 2020)

In this case report, we reflect on the different approaches Sophie, a person with lived experience of neurological physiotherapy and Louise, a senior physiotherapy lecturer brought to a session with final year students and the benefits achieved by developing a partnership approach.

Report

Louise: My name is Louise, and I am a neurological physiotherapist by background and senior lecturer in physiotherapy. I invited Sophie to assist with a final year undergraduate physiotherapy teaching session to provide her lived experience expertise. Students often face challenges and feel anxious when learning about neurological disability. The learning outcomes for the session were for the students to understand the complexity of adult cerebral palsy (CP) and to learn how to assess clients with a neurological disability. My plan was to conduct an assessment of Sophie during the lecture with the opportunity for both Sophie and I to explain the process to students and for them to ask questions.

Prior to the session I met Sophie in her supported living accommodation. This was an opportunity to get to know her and explain the session context. It felt important to meet Sophie in a setting of her choice and for her to feel as prepared as possible.

Sophie: My name is Sophie. I am a post-graduate student specialising in Early Childhood studies. I am passionate about sport and education and regularly contribute to the PIER partnership at Bournemouth University. I also happen to have ataxic cerebral palsy. When doing a session with Bournemouth University physiotherapy students it gives me anxiety as I do not know much about the subject apart from the interventions I have had myself from physiotherapists. This has not been consistent since the age of 7 or 8 when I finished Conductive Education (CE). CE is a non-medical approach to rehabilitation developed in Hungary. It differs from other rehabilitation techniques as the therapists' skill is relied on less than the person's own participation and initiative.

In my experience, it has been hard to get an NHS physio and because of the lack of consistency I have not always complied with treatment plans, even in adulthood, preferring to live my life rather than fixate on improving my physical performance.

At the time of this session with the students, my attempt to engage with physical exercise was a given in my life and based on attending the gym and going swimming. In the medical world this is thought of as physical therapy. In my world this was something I enjoyed and allowed me to get away from my living environment. Due to my understanding of cerebral palsy, I can put this into a medical context, seeing improvements in my physical development. In the gym I focus on reducing pain with the added bonus of increasing my mobility. Because I am likely to fall, I restrict myself to my wheelchair when I am on my own. My ability to transfer onto the loo is also important to me. I am looking at utilizing my mobility equipment to the best of my ability to get away from pain but also increase my independence. The ability to do a standing transfer is essential to my university experience, as time away from the supported living unit will be limited if I am unable to do this. Therefore, making university experiences impossible for me due to the lack of support staff at university.

Louise: Sophie attended the teaching session arriving in her wheelchair and with a Quest walker. There was a 'Question and Answer' session guided by pre-planned student questions. Sophie answered the questions talking about CP and describing her student life. Sophie had an interesting narrative which went in a range of directions covering several aspects of her life. The students were actively listening and engaged. Because Sophie was also a university degree student, she was able to connect with the students about academic

study and writing a dissertation and so also spoke about this. I enjoyed the discussion with Sophie generated by students' questions. Sometimes, I feel anxious with sessions involving a visitor. I feel I need to achieve the learning outcomes by keeping to my checklist and that I need to perform and teach well. However, in this session I was aware that my focus was on setting the scene so that Sophie could tell her story. I did have a check list, but I was surprised by the direction of the conversation. This was guided by Sophie and the students and the discussions they were engaging in. I was conscious that I needed to allow Sophie time to tell the stories that were important to her and let her take the lead.

Sophie: One interesting thing about the session is how I see CP. I don't focus on the ataxic part of CP which the physio assessment does. Obviously, this is medically relevant to professionals, and it is important to convey this. I think my academic background means that I can bring a social perspective to a medically focused profession. For me this is important. When I started my work with Louise, the sessions were interesting to me as I do not know about ataxia. Looking back, I realise that what is important to me is looking at life goals instead of goals that make a person walk just for the sake of walking.

Louise: Sophie explained that she used the Quest walker to improve her life, but not always to allow her to be mobile. This is an interesting and profound insight for me into her view of mobility aids. Sophie demonstrated how she used the Quest walker. I then demonstrated a physiotherapy assessment for ataxia and co-ordination (difficulty controlling motor movements).

Sophie: I haven't often been assessed in the same way as Louise assessed me during the session. Previously, there has been much more of a focus on the ability to walk and move around rather than hand control and upper limb mobility. I associate upper limb ability with Occupational Therapists (OTs). The assessment Louise conducted was unfamiliar to me apart from when I have had physio when injuries took place. The students could have learnt from knowing this, but at the time, I wasn't confident to say this to the students nor Louise.

Louise: I have only fully understood the insights shared by Sophie while we have been working to write this paper and as we have together reflected on the session. One of the key lessons I have learnt is that we as educators need to create an environment that allows the person with lived experience to feel comfortable to share their insights. In order for this to happen we as educators need to remain open to this possibility whilst teaching. One of the students commented in their feedback that they found the different perspectives from the physiotherapist and patient had facilitated their learning. This reinforces to me that we do need to give the patient permission to be open to sharing their experiences. This is supported by student feedback which stated "thank you so much for being open and willing to get involved in the session. It was lovely to meet you and learn so much about CP and how much you do day to day".

The ability to demonstrate clinical skills in a session with 25 students observing can feel overwhelming as a lecturer. Although an experienced clinician I wouldn't usually have 25 people observing a patient assessment. Sophie was my primary focus in terms of her fatigue and safety. I also wanted to ensure that the students maintained their engagement in the session when the focus shifted from discussion to demonstration. There was a lot to think about and Sophie and I worked collaboratively with each other which supported me to feel more comfortable with Sophie and the students.

Sophie: One of the issues I saw from the very first session with Louise is around my fatigue levels. I plan for day-to-day tasks, and I do not often have other people worrying about these issues. However, I do not normally talk for this long in a structured way to a classroom of 25 students all focusing on me; waiting for me to reflect on my physiotherapy experience. I was tired so I'm glad that this was addressed and was refreshing albeit a bit confusing. Again, it is something I don't always talk about, and medical people need to understand about fatigue. Perhaps I would be more conscious about talking about CP and fatigue in the future.

Louise: Teaching a physiotherapy assessment involves following a list of tests and standardised outcome measures. This can be a formulaic process using check lists. Often this results in the students focusing more on the list and being worried about covering all the tests, rather than remaining patient centred. In this session with Sophie, aspects of an assessment were covered by the initial dialogue which enabled the students to get to know her. One student commented in the feedback "amazing insight into your life, showing us the effects of ataxia CP, but more importantly how to adapt and achieve your goals". There was generally agreement that observing the assessment of ataxia was beneficial to the students. The student feedback stated that they had learnt "different aspects of the ataxia assessment and how to make it functional" and also that they could make links from previous learning "it helped me to revisit previous knowledge from my second year in a strong way; was especially helpful to work with Sophie to go through various physical tests for balance, strength etc". There is still a risk that students will perceive this assessment as a formulaic process. Their feedback, however, shows that students were able to understand that the patient decides where they are aiming and not the healthcare professional. This suggests that the students viewed this assessment from a more multi-dimensional patient centred perspective. Sophie was able to present a more holistic and social model of disability and identify what was important to her and student feedback showed that they had understood the importance of this. Dispelling the notion that patients need to fit in with societies' norms, for example, walking. Instead, patients can be given the options to perform the tasks with ease such as using a walker or wheelchair.

Sophie: If I was going to do this session again, I could talk about the turning point in my life regarding how I've discovered how to use equipment and mobility aids appropriately and to my advantage. Many professionals have seen the use of a wheelchair as a failure. This should not be the case for people especially with CP, my life has improved because I use a wheelchair.

Louise: The session with Sophie was both challenging and enjoyable. Challenging because I had 25 students and I wanted the students to understand the complexity of CP and ataxia. It seemed that once I was comfortable with the focus and direction that Sophie took the session I relaxed and began to enjoy the way that Sophie and I led the session together. The session was enjoyable because I learnt more about Sophie and CP as well as about myself as an educator. Although Sophie and I approached the session from different perspectives we were able to work together to support the students to gain rich insights. The take home message to the students was to look at a neuro assessment in a holistic way. I feel that I need to continue to take this perspective into my teaching practice to capture the multifaceted nature of neuro-physiotherapy. Checklists in teaching assist us to be prepared but we also need to grow in confidence to feel comfortable even when we deviate from the proposed plan.

Discussion and conclusions

Sophie and Louise's reflections provide a useful case report for considering the nature of relationships and power dynamics when involving people with lived experience in physiotherapy education. Louise had a plan in mind for the session and had created checklists of what needed to be covered based on the required Intended Learning Outcomes (ILOs) and technical expertise. Sophie however saw this differently. She was mindful of the technical expertise the students needed to develop but also that these were different from her own motivations, priorities and goals.

In the 1980's the sociologist Habermas developed the concepts of life worlds and system worldsto explain the challenges of developing genuinely equal partnerships (Habermas 1991). He proposed that the system world is motivated by priorities including technical expertise, processes, and efficiency. The life world however focuses on everyday realities and is motivated more by cultural and social norms and the nature of relationships. Specific conditions are required for an interchange to occur due to the different priorities and structures of these two worlds (Habermas 1991, Fraser 1990). In sharing her lived experience Sophie brought a lifeworld perspective to the process of conducting a physiotherapy assessment with someone with CP and ataxia. Louise started to create the conditions for this meaningful interchange from the start by meeting with Sophie in her home environment and was open to sharing control within the session itself. From the start of their planning Sophie and Louise sought to shift the power dynamics that can exist between educator or practitioner and patient. This created a new way of working which at times felt uncomfortable. Both Louise and Sophie reflect on feeling anxious at different stages of the process. This perhaps reflects these shifting power dynamics and expectations regarding roles. Sophie for example, questions the extent of her knowledge and expertise and Louise feels pressure to perform and teach well.

This more equal partnership however led to both Sophie and Louise being able to direct the focus and direction of the session. This resulted in a much more holistic and meaningful exploration for students regarding the process of conducting an assessment to one that was more in depth and mindful of the complexities of real-life practice. It involved focusing on the life goals that are important to Sophie and addressed Louise's concerns by preventing an over-reliance by students on standardised outcome measures and checklists in favour of a more patient-centred approach to assessment. Sophie and Louise role modelled best practice for the students by genuinely showing how an assessment and a session can be conducted in partnership. As educators, the use of role modelling can have significant impact on student learning and in developing best practice.

In this report, and throughout this series, we have sought to critically reflect on the process and impacts of collaborating with people with lived experience in physiotherapy education. Our goal has been to share our experiences and contribute toward the development of a culture and framework for high quality, evidenced informed public involvement activity in physiotherapy education. We hope that by doing so, other educators including people with lived experience will contribute their own knowledge and expertise to develop this empirical evidence base for lived experience education.

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