Reflections on Powerful Relationships Using the Example of the Concept of Service User Involvement

Mend the Gap: Collaborative Learning with Service Users

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1. Introduction

This chapter involves an attempt to contribute to the book's aim 'to identify and fill existing gaps in the discourse on participatory teaching while always focusing on an engagement with ambivalences, paradoxes, and contradictions'. I will focus on the preface's suggestion that service user involvement could be a starting point for developing participatory teaching in Germany. To this I would respond that maybe it could, maybe it couldn't, it depends how service user involvement is done. Although the background and current practice of service user involvement in higher education in the UK is inevitably different in many ways from in Germany, there are similar issues to be critically considered in both countries. The chapter involves a reflection on a module I have developed and delivered at Northumbria University, which has also been run by Northumbria University's partner institution KAPLAN in Singapore. The module is entitled Mend the Gap: Participatory Learning with Service Users and is strongly rooted in ideas about both service user involvement and participatory teaching. It has run annually for several years now. I begin by outlining some of the background to service user involvement as an approach in higher education in the UK to explain both what the module is and is not about, to characterise it as involving an approach which values both experiential and theoretical knowledge. I then focus on its delivery at Northumbria, contextualising this in terms of the wider discussion in this book, and I briefly consider its development in Singapore. Finally, I draw conclusions relating back to the initial suggestion. I draw on written reflective statements about their involvement made by students and service users who have been part of this project and acknowledge thanks to all who have

kindly contributed their thoughts. I write as a disabled activist and academic who has been involved in the UK disabled people's movement and with the critical discipline Disability Studies since the 1990s.

2. Service User Involvement and Participatory Teaching

Though the UK service users' movement has evolved to include an increasingly diverse number of service user groups – including older people, people living with HIV/AIDS, people with chronic and life limiting illnesses and conditions, carers, and other people with experience of social work systems (cf. Beresford 2010) – it has its origins in the campaigning activity of the disabled people's movement towards the end of the 20th Century (cf. Branfield et al. 2006; Beresford/Carr 2012; Beresford/Carr 2018). This movement was characterised by rejection of the narrative put over by the large charities that different impairment groups had separate interests and involved the coming together of people with a wide range of impairments – people with physical and sensory impairments, mental health service users and survivors, people labelled as having learning difficulties. While it was recognised that people's impairments may be different, it became increasingly recognised that disability involves similar processes of control, exclusion and marginalisation. The extent to which disabled people became active in the movement depended on a number of factors, not least the extents to which their lives were subject to intrusion and control by 'caring professionals' and their self-identities colonised by perspectives of the non-disabled.

Rooting their ideas in their own formulation, the social model of disability, which made a distinction between impairment, identified as an embodied condition, and disability, regarded as a form of social oppression (cf. UPIAS 1976; Cameron 2014a), through their own organisations disabled people collectively protested at the paternalism which characterised the way human services, including social welfare and education services, had traditionally been organised. They critiqued the individual or medical model, which identified disability as unfortunate limitation and abnormality arising from impairment (cf. Oliver 1996; Cameron 2014b), arguing that disability involved the exclusion of people with impairments from ordinary community life through the establishment of physical and social barriers. Physical barriers to public buildings, places of employment, shops, places of leisure and entertainment, public transport, housing, places of worship, schools, colleges, universities, and so on, prevented access to the social mainstream (cf. Swain et al. 2014; Clark 2014; Heaton 2014; Clifford 2020). Social barriers which involved stereotyped and demeaning cultural representations, for example, led to disabled people experiencing condescending and absurd interactions with the non-disabled in everyday life, the non-disabled typically making strange, oppressive and

judgemental assumptions about the meaning and experience of impairment (cf. Morris 1991; Cameron 2014c; Cameron/Smith 2024).

An understanding was developed of disability as a historical phenomenon, emerging at the time of the 19th Century industrial revolution, to do with the requirements of the capitalist system for a conformist, docile population of workers who would do what they were expected to, in the time required, in the manner expected (cf. Barnes 1997; Fromm 2001; Elias 2001; Cameron 2014d; Foucault 2020). People with impairments had posed a challenge to this new regulated society, to the assumption of normalcy as standard, and had been institutionalised and otherwise removed from sight. Disabled scholars Albrecht (1992) and Oliver (1996) identified the emergence of a 'disability business', an army of professionals – e.g. social workers, special school teachers, occupational therapists, physiotherapists, music therapists, arts therapists, day centre workers, etc. – which appeared across the 20th Century to manage the lives of disabled people in the segregated settings on the margins of society where they were required to spend their lives. The so-called 'scientific' research with and in which these pseudo-professions rooted and justified their practice was founded upon ideological assumptions about the 'personal tragedy' of impairment and the desirability of normality. Disabled people were regarded largely as problems in need of fixing and professional 'care' (cf. Oliver 1996; Cameron 2014e), and services were organised accordingly. The hierarchical reasoning underlying the planning and delivery of services, in which professionals 'did' and disabled people were 'done to' was identified as creating dependence (cf. Swain/French 1998; McKnight 2005), as were ongoing programmes of higher education which largely continued to teach the individual model to new generations of human service professionals.

It was this which disabled people opposed as they demanded inclusion in ordinary community life on their own terms: as people with impairments rather than as flawed normal people; as people with their own valid knowledge, understanding and experience of life, rather than as not-quite-good-enough human beings. The disabled people's movement required that impairment be recognised and included as a fundamental part of the diversity of human life – as a part of human experience that can be learned and gained from – rather than regarded as a cause for pity and condescension.

The major victory of the UK disabled people's movement resulted in the establishment of the 1995 Disability Discrimination Act, later superseded by the 2010 Equality Act. This, however, has long been regarded as partial victory (cf. Swain/French/Cameron 2003; Cameron 2023), as it enshrined in law an individual, medical model of disability. The Equality Act 2010 states that 'you are disabled if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities' (GOV.UK 2025). In other words, disability is identified as something 'wrong' with some people's bodies, which has

nothing positive to offer and is abnormal. While another important victory of the disabled people's movement included the establishment of rights to be involved in the planning and delivery of public services, in areas of health, social work and higher education, for example, the underpinning of such activity by a personal tragedy definition of disability has led to the persistence of contradictions.

Since 2003, for example, it has been a requirement that service users are involved in recruitment and education processes within university social work qualifying courses (cf. Beresford/Carr 2012). While there is undoubtedly much that is positive to be said about service user involvement in professional qualifying courses, such as social work degrees, caution has been expressed too. Eriksson (2018: 834) has observed:

> when transformed into a public concept, service user involvement becomes something distinctively different from service users mobilizing themselves to make a social impact. Rather, it becomes a case of service users being activated in welfare organizations' internal evaluation, development, and quality management.

Eriksson suggests that when collective voices become incorporated within public institutions, they tend to be come individualised and 'tamed' to comply with institutional logic: not to be too critical, or radical, or too far-reaching in their demands, but to be constructive and to focus on issues where common ground can be found:

> While the idea of user involvement was initially formulated from outside the public administration by an independent grass-roots movement … today user involvement is largely a political and organizational concept managed from above (Eriksson 2018: 834).

The shift in descriptions of service users to the currently fashionable 'experts by experience' or 'educators by experience' reflects the individualisation Eriksson speaks of. Shaping Our Lives (2024), the UK national campaigning network of service users, identifies 'service user' as an important political identity – a collective identity – involving an assertion of entitlement to receive welfare services. This is important in an economic climate where much of the welfare system has been decimated as successive UK governments have imposed punitive austerity measures. The terms 'experts by experience' and 'educators by experience' place emphasis on personal, lived experience as individuals – without the collective, political consciousness and theoretical understanding developed within the disabled people's movement. There is much talk about diversity and inclusion, reflecting perhaps an understanding that diversity can enhance the competitiveness of the university, but little talk about oppression and discrimination (cf. Cameron 2023b). The social model, which identifies disability as oppression, is discounted in the colonising view of the universities. Dis-

ablism is identified as an administrative issue, to be resolved through better management and more 'niceness'. In the meantime, disability is still characterised as as something 'wrong' with people, something people 'have'.

In a 2017 national research report, Shaping Our Lives (2017: 8) identified common frustrations service user representatives felt about their experiences of service user involvement. These included:

- frustration at it taking so long for anything to happen;
- annoyance as it became clear that it was all just a tick box exercise;
- difficulty as organisations had their own way of doing things which needed to be understood;
- feelings of being patronised and not listened to;
- a feeling of a lack of real commitment by professionals to actually doing anything;
- service user involvement being treated as an add-on item at the end of the agenda, when professionals would start to excuse themselves;
- a sense of pointlessness as professionals only asked those to talk who could be trusted to say what was wanted.

Service user involvement can be a valuable and important thing, but it is often made a less than satisfying experience because of fundamental power inequalities (cf. Cameron/Molloy-Graham/Cameron 2020). I recall while gathering data for the PowerUs Charter (2024a), consulting disabled members of a service user group involved with a social work degree at a Northeast university, the service users always checked, making eye contact with the non-disabled programme leaders, seeking their permission before they answered any of my questions. However much is said about valuing and listening to service users and experts or educators by experience, so long as higher education professionals adhere to an individual model understanding of disability, real change is unlikely. So long as service user representatives have their voices tamed within these processes, I'd argue that to an extent this involvement is a bit meaningless.

I wanted to make this background clear to emphasise the fact that Mend the Gap, while firmly rooted in a service user activist perspective, is not really the same as much that currently happens under the description service user involvement in many UK universities. It is grounded, instead, in the social model principles established in the UK by the Union of the Physically Impaired Against Segregation in 1976, and in the liberatory education principles established by Paulo Freire in his 1970 book *Pedagogy of the Oppressed*. In Mend the Gap we talk about oppression.

3. Module PP0549: Mend the Gap at Northumbria

The Mend the Gap module has its origins in 2011 in a collaborative project between Lund University in Sweden, Lillehammer University in Norway and Shaping Our Lives (cf. Askheim/Beresford/Heule 2016; Heule/Knutagård/Kristiansen 2017). It had been observed that many social work students had done their learning in classrooms and perhaps in a couple of structured placement settings, then had come out as qualified professionals with power to make decisions about people's lives, without having ever really talked to any of the recipients of their services, or without really having an understanding of the issues service users experienced in their daily lives. As well, it was observed that many people who used services had views about professionals as all-knowing, as experts, as all-powerful, rather than as harassed people struggling within large bureaucracies.

Bringing students and service users together to learn from each other was seen as a way of mending the gaps in knowledge that existed between them. About beginning together to identify small changes that could be made to the way things were done. About learning from service users' experience and understanding. The early projects involved people with addiction issues and homeless people in Sweden (cf. Askheim/Beresford/Heule 2016; Heule/Knutagård/Kristiansen 2017) but projects have since developed in many European countries and beyond, working with many different groups – refugees, asylum seekers, different groups of disabled people, older people, children of refugee parents, for example. These diverse projects are all part of an international network, PowerUs (cf. PowerUs 2024b). I learned about the gap mending approach attending a conference at Lund in 2014 through my involvement with Shaping Our Lives.

The undergraduate BA Joint Honours degree at Northumbria University, of which Disability Studies had been a part, was shelved in 2018 due to departmental restructuring. Several new degrees emerged, among them BA (Hons) Guidance and Counselling and BSc (Hons) Health and Social Care. Suggestions were requested for Level 5 (Second Year) options modules for these degrees (students could choose from various options which module to take as part of their second semester studies). I developed and proposed an outline for a module entitled Mend the Gap: Collaborative Learning with Service Users, which was validated and first ran at Northumbria in 2019 and at KAPLAN in Singapore in 2020. Service users involved have included asylum seekers, refugees, disabled people with various physical, sensory, cognitive and emotional impairments, transgender people and migrant workers. This current year service users at Northumbria were people with experiences of emotional distress, autistic people, a woman labelled as having learning difficulties and transgender people.

The module at Northumbria runs over 10 three-hour sessions and involves a small, balanced number of students and service users coming together to share

and reflect upon experiences and ideas. It is all based on Freire's (1970, 2017) ideas about education for liberation. This requires moving away from a view which sees the teacher as the all-knowing expert and students as empty vessels to be filled with knowledge. Instead, it involves constructing a situation where participants can come together to share their own experiences and personal insights to develop a critical perspective based on a collective understanding. Applying principles of participatory teaching, it is about creating a situation where the students can learn from the service users, gaining respect for their experience and understanding that the knowledge gained from lectures, books and journals is not the only valid knowledge. There is a recognition of the importance of theory as a tool for the development of critique, however, and each session starts with a short(ish) lecture on themes identified in the first week's discussion. This gives context to the emerging conversations, and involves an attempt to establish praxis, in which theory and experiential understanding fuse to lead to politically aware action. My role is as a facilitator rather than as a teacher.

The first week of the module began with an introductory lecture outlining Freire's principles. Relating these to the context of Mend the Gap involved developing an understanding that:

- relationships between professionals as *doers* and service users as *done to* involve relationships of domination and control which require to be challenged so that service users gain agency and self-determination;
- the traditional understanding that professionals' knowledge counts, while service users' knowledge doesn't count, impacts negatively on the relationship for both sides;
- through dialogue between professionals and service users, a truer understanding of how things really are will emerge;
- it is a requirement, if they want to take control of their lives, that service users free themselves of the low expectations and the internalised oppression that has been instilled through the experience of domination by professionals.

Following the introductory lecture, students and service users organised themselves into small groups to begin talking with each other and to identify issues they wanted to explore over the course of the module. Most of the students involved are quite young – 19 or 20 years old, while the service users, aged from their late 20s to their 70s, usually have long and interesting histories behind them.

As student Katie Lewins put it:

> Having external students, not knowing anything about them beforehand, is awkward at first as they are older and new. But the more we communicate, and the more sessions attended, the more comfortable I feel working together.

Issues identified during the first session this year included: discrimination, misdiagnosis, sexism, class, domestic abuse, gender abuse, roles as natural, diagnosis, bullying (acceptance of poor treatment), 'I'm the problem' (accepting passive roles imposed), system reinforces it, appearances, power and professionals, medicalisation and power, dealing with institutions, asking for help, fear, relationships with people, compliance, empowerment, 2010 Equality Act, psychiatrists and medicalisation, different professional views, being heard and believed.

Commenting on why she found the lecture part of each session important, service user Natasha Downs noted:

> I enjoyed the lecture portion of the course as I found learning theory which complemented the understanding of my own lived-experiences insightful. I appreciate what this symbolised structurally— both are equally useful as sources of knowledge.

In advance of each session, I sent out readings and journal articles relevant to each lecture both to students and service users, making it clear that these were to be regarded as resources for people to use if they wanted, but not required reading. Service user Cherry Lola Lee reflected that:

> Having course resources shared was very beneficial, placing all participants on equal footing with access to information, promoting worth and equal standing of service users who are entering an academic setting which of itself challenges institutionalised oppressive dogma.

Following the lecture, after a break, groups spent the rest of each session working together on the development of a project, to be presented during the last session in Week 10. As a Level 5 module this counts towards students' degrees and so has to be formally assessed. Presentation of project work forms one part of the assessment and students are required to write a reflective diary as the other part. I never have any idea at the start of a Mend the Gap module what kinds of projects will emerge. What develops is all down to the members of the groups, the students and service users, in collaboration. In past years groups have produced books, newsletters, Talking Heads videos, podcasts, and developed a women's safety campaign. This year, one group produced a series of reflective letters to their younger and older selves. Another produced a podcast based on interviews with the service users and student reflections on what they had learned. The third developed an interactive exercise highlighting the ways structural issues are often experienced as personal troubles, identifying and building a wall of barriers then coming up with ways to knock this down. Student Niamh Page wrote:

> I found that this was the part I was most excited for each week, to share insights with one another and really grasp how people viewed the system through their own experiences. I really enjoyed the freedom of choosing the creative way of producing this work and what subject we could focus on.

While each group ended up getting a good mark for its presentation, as far as I am concerned the marks students got for their project work was secondary to the learning which emerged as an outcome of the collaborative processes. I received numerous statements, from both students and service users, saying that it had been the process involved, in listening to and learning from each other, that had been of most value.

As student Emily Gibbinson put it:

> You feel like you have gained a different perspective once you have heard about what it felt like … when listening to life experiences.

Service user Libby Walker wrote about why she thought this approach was important:

> The process is what worked, we became united and merged, the barriers were shifted organically. I like feeling like I and other service users had input in the students' journeys as the future generation of health care workers. Students learned to be critical about power, control, equality, social structure, social norms, cultural constructs, and are clearly aware of the gaps now after this module.

Service users were registered as students for the course of the semester, giving them access to the University library and other benefits, and had expenses covered. They also received a certificate of attendance but unfortunately gained no official accreditation. The reasons for this are financial, to do with the fact that students pay fees to do their degrees and involve complications around that. Nevertheless, both groups, service users and students, recognised the value of what was happening.

Niamh Page recalled:

> I have been so glad to have met the two ladies in my group … that they were able to open up to us all about their trauma and experiences to help us really gauge an understanding of what we can challenge when we become healthcare professionals ourselves.

Niamh's statement makes it clear that, while the group discussion and collaborative learning was something she enjoyed, it did involve listening to personal accounts of traumatic and upsetting experiences. As service user Judith Culham-Elsdon observed, though, students also spoke about their own gender-, class- and disability-

related experiences of oppression, a collective understanding emerging of the structural nature of oppression: of its subtle transmission in the practices of everyday life, and of the way it is often replicated in professional practice (cf. Reeve 2014; Thomas 1999; Young 2022).

> Talking about our lives and traumas is hard as it brings up suppressed feelings and triggers. For all the students are young, they have experienced traumas too which has led them to take the education path they have. We think the students have got a lot from the course as it has allowed them to have a better understanding of what is ahead of them.

I would be dishonest to try and pretend that every part of everybody's experience of this module was without tension. Heather Harvey discussed resistance she encountered from students in one of the groups to her accounts of negative experiences as a service user:

> The students did not use us as a resource. I felt that they were very guarded and defensive of 'the system' (aka doctors). Any criticism stemming from my personal experience was met with disdain.

Heather's point here was endorsed by service user Ana McKenna:

> One of my strongest memories of group interaction was trying to explain to a student how it feels to account for yourself to a medical or quasi-medical authority, something I have personal experience of. What stood out to me was her shocked insistence that doctors are simply trying to help patients, which to me seems a dangerously naive viewpoint.

Some resistance should perhaps be expected, particularly if service users' accounts run counter to what is being 'officially' taught in the classroom. Strong identities as students of Health and Social Care were involved, and in this module many assumptions underlying practice were brought into question. Any process requiring people to examine deeply held beliefs about who and what they are about can be disturbing and unsettling. The voices of real people talking about their experiences as service users turned expectations upside down. Where there was tension in this one group, it made for a sometimes-difficult process, though good project work was produced in the end.

4. Mend the Gap in Singapore

Rather than involving a range of service users, each of the nine Mend the Gap iterations at KAPLAN in Singapore has involved students working with people from one service user group: either, initially, migrant workers or, later, transmen and transwomen. Yeow Beng Zhen, who runs the module in Singapore, makes the following observation:

> Allowing the students to be engaged in real life issues brought forth by service users, it got the students to re-examine their own lives, while bringing the knowledge learned from the service users at the classroom to integrate back to what is happening around them. Students were able to connect to their own past or/and present struggles, and them identifying different parts of themselves within the narratives of the service users. To be able to connect with another fellow person at such a level, and allowing vulnerabilities to come through, this is certainly one example that the usual educational system could not deliver and achieve.

In terms of the service user involvement approach adopted in this module, importance is placed on making links between structural and personal experiences of oppression and of how these are manifested in everyday life. In Young's (2022: 41) terms, structural oppression involves:

> the disadvantage and injustice some people suffer not because a tyrannical power coerces them, but because of the everyday practices of a well-intentioned liberal society.

Structural oppression is not necessarily the outcome of intentional acts and behaviours deliberately calculated to hurt or demean but is characteristic of the ways we have all been educated and socialised to relate to each other. It goes on, unnoticed, in everyday life. It is the outcome of sets of social arrangements organised to advantage some and disadvantage others. Everybody is caught up in these relations of oppression (cf. Ruth 2019), but this is not always clear to see. Oppressive social relations of class, gender, race, disability, and so on, are obscured by their familiarity. Meeting with and learning from service users enabled the Singapore students to reflect on their own positions in relation to these oppressive social relations.

Coen Teo, a Singaporean transman who participated in Mend the Gap, has commented:

> Sharing my life experience with students offered them a valuable opportunity to meet a real service user and gain firsthand insight into the challenges we face. By hearing directly from someone in the transgender community, students were able to better understand the complexities of our struggles, beyond what can be

> learned through textbooks or classroom instruction. This personal interaction helped to humanize our experiences, contrasting with the often inaccurate or sensationalized depictions of transgender individuals in the media or through third-party narratives.

Earlier I identified this module's origins in the PowerUs project started at Lund University. I know that in developing this module – which, as far as I am aware, as a member of the PowerUs network, is the only Mend the Gap module regularly running at any higher education institution – I have made sure of a balance between theory and experiential understanding. This, I think, is down to my own subject position as a disabled activist academic, as a disabled person committed to, and whose life has been transformed by, the critical understanding the social model gave me. Perhaps Mend the Gap might be run differently elsewhere. My point, though, is that it seems to work, and it makes a real difference to students' and service users' understanding. It has been piloted at Northumbria and in Singapore, and I would hope now that somebody may take it up in a German-speaking country.

Sohag, a migrant worker in Singapore, commented:

> This lesson is very good because students need to learn from different people's life. This lesson helps students learn about workers life. I am very happy because student get to know about our problems/struggles, and they show concern for us. They give effort to think of solution. The students get to know workers life and I also understand more our Singapore student life is.

Sohag's words sum up for me what the module is all about. In Freire's terms, it is about education for liberation.

5. Conclusion

In the introduction to this chapter, I expressed uncertainty about whether service user involvement might be a starting point for the development of participatory teaching as it is currently implemented in Germany. I suggested that it might be, or it mightn't be, it depends how it is done. There are issues to be addressed relating to Eriksson's concerns about the taming of service users' voices once they have been incorporated within institutional practice. Unequal power relationships and professionals' persistence in framing disability discourse in individual model terms, as something 'wrong' with people, involve a stifling of the possibility for meaningful criticality. There are good reasons to be cautious. On the other hand, when service user involvement is underpinned by a critical perspective, and has as its aim the es-

tablishment of praxis, of emancipatory action informed both by lived experience *and* by theory, it could be just what is wanted.

At Northumbria, Module PP0554 Mend the Gap: Collaborative Learning with Service Users is a Level 5 options model for students of BA (Hons) Guidance and Counselling and BSc (Hons) Health and Social Care. It involves a very small number of students each year and brings them together with a very small number of service users. Though it has transformed things for many of those who have taken part, it hasn't yet made much of an impact beyond itself, though service users involved have made recommendations that the approach should be taken up more widely. Service user Rachel Weatheritt has suggested:

> Mend the Gap should be a required part of every professional qualifying degree, not just optional and not just at Northumbria. Teachers, social workers, nurses, police, physios and OTs, as well as counsellors and health and social care. Wherever any future role involves power relationships, students need to be learning from service users like this.

In the meantime, structural oppression persists in countless everyday interactions and assumptions made about service users. It is ubiquitous and goes unnoticed. Part of the issue is that, as Martin (2003: 1) expresses it:

> We are not trained to think of the repetitive activities and apparently banal objects that make up our everyday experience in an intellectual way.

I am not suggesting that Mend the Gap is the perfect module or that it is without faults. As an organic process, there are places where it lacks organisation and structure, and no doubt it could, should and would be done differently in plenty of ways if it was developed elsewhere. But there is something at its core – in terms of the opportunities it creates for service users' voices to be heard, for students to learn directly from service users, and for service users and students to come together in a spirit of critical enquiry – seeking new ways to mend gaps in knowledge between them – which I think is very important. As service user Cherry Lola Lee states:

> I've learnt much about oppression. It's entrenched, it's extremely difficult to challenge and is insidious …. We impact people and are affected by others to varying degrees according to oppressive stereotypes, prejudices and discriminations of class, gender, race, disability. Hierarchical power divisions are reinforced through oppressive behaviour which holds us back individually and collectively from reaching our full potential. Working in groups collectively on a task provides a premise for unification. Without trying there's no challenge and therefore no change. I'm pleased I took part.

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