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## Are perceptions of disability changed by involving service users and carers in qualifying health and social work training?

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### ABSTRACT


10 This **article** reports the findings of two small-scale qualitative studies at an English university which engaged service users and carers (SUACs) as researchers in co-production with an academic researcher. Findings were that SUAC participants reported considerable levels of self-transformation via involvement in training health and social work professionals. Students reported heightened empathy and having had their perceptions about disability challenged. Further research regarding whether any learned values and attitudes regarding disability are carried through to the world of practice is recommended.

### ARTICLE HISTORY

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### Points of interest

- 20 • Service users and carers (SUACs) contribute to the qualifying training of health and social work professionals in UK **u**niversities. This inclusion of SUACs is mandatory for nursing and social work courses.
- There is little evidence to demonstrate that the involvement of SUACs in this work has been effective, findings to date having been inconclusive and largely concerned with student learning outcomes.
- 25 • This **article** reports on two qualitative studies, led by SUAC researchers, into whether perceptions of disability change as a result of SUACs being involved in professional education, from a student perspective and from a SUAC perspective.
- 30 • Findings were that student perceptions regarding disability **changed** as greater empathy and understanding of people with disabilities  unique individuals emerged. The second study reported transformative changes in SUACs with regard to confidence levels, skills acquisition, new friendship networks and moving on to paid employment.

## Introduction – attitudes to disability in the United Kingdom

Most research indicates that prevalent attitudes towards disability remain negative (Hardeep and McCarthy 2014; Stanislund 2009) and largely influenced by the medical model (Heng 2015) rather than by an appreciation of the ways in which societal structures oppress disabled people. The lack of positive role models in public life and negative media representation of disability are further factors affecting the public from whom new recruits to the professions within health and social work are drawn. For example, media coverage of the 2015 Germanwings plane crash emphasised the alleged suicide of the co-pilot who had a background of mental illness – ‘Madman in Cockpit. Crazy Rookie Pilot Murdered 149’ read the headlines of the *Sun* newspaper. The UK mental health organisation MIND responded in a very balanced way, stressing that pilots with experiences of depression will have flown safely for years and that the Germanwings tragedy was exceptional. However, the damage from such reporting is hard to undo even by such positive and swift responses, and cumulative negative perceptions on issues such as disability soon consolidate. Recent scandals in the private sector and public sectors regarding disabled people, notably at Winterbourne View (Department of Health 2012) and at Mid-Staffordshire NHS Foundation Trust (Francis 2013), underline that oppressive and abusive attitudes and practice still exist in contemporary settings, despite the existence of a plethora of policies and regulations.

Theorists from a range of different perspectives present disability as having negative connotations (for example, Becker 1963; Goffman 1963; Scheff 1984) with Goffman’s seminal work on stigma perhaps remaining the most influential. Goffman viewed stigma as being responsible for excluding individuals from full social acceptance, going on to suggest that certain characteristics will always be viewed as abnormal and deviant. Alternative positions on the social construction of disability, often promoted by the voices of disabled people (for example, Branfield and Beresford 2010) have had less influence on contemporary society, despite policies of inclusion being characterised UK education and social policy over recent decades. Söder (1990) suggests that ambivalence, rather than negativity, towards disability is perhaps a more significant factor in attitudes than had been reported wherein reactions towards disabled people are brought about as a result of conflicting values.

## The changing environment of health care and social work

The work carried out by health professionals and social workers prior to the incursion of business models in the 1970s relied upon practitioner autonomy and individual professional judgement, with management following the lead given by professional decisions. For example, social work was casework and relationship based and the emphasis remained on ‘remedial rather than preventative social work’ (Harris 2008, 669). In the promotion of the use of relationships in health

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care and social work, the professional focus was on helping patients and clients, rather than on meeting targets and budget compliance. The 'helped' were not viewed as being in a position to influence arenas such as professional education and practice which were viewed as the exclusive domains of professionals. The ground-breaking work of Mayer and Timms (1970) presented the views of disabled people using health and care services as voices that needed to be heard alongside those of the professionals and challenged a hitherto patriarchal view of disabled people and others who had been seen as 'deserving' and needing 'helping'. The election of a Conservative Government in 1979, whose ideology promised to lessen the role of the state in individual and family life, heralded an attack on social work and determined to manage the spiralling costs of the National Health Service. The subsequent emphasis on consumer and customer rights, however, did not encompass those of disabled people, despite the introduction of policies such as the Independent Living Fund in 1988, since abolished by the Coalition Government in 2015 (Porter and Shakespeare 2016). The voices of disabled people were largely unheard as government pushed for a more managed, prescriptive and evidence-based foundation to health and social work services.

The consumer model did offer an alternative model to the model of patriarchy, but cutbacks and the consequent retrenchment of welfare and the privatisation of state-owned services brought about by a succession of neoliberal governments led to social workers and allied professionals operating in a quasi-business environment (Harris 2003) wherein job degradation and rising levels of dissatisfaction were reported (Ferguson, Lavalette, and Whitmore 2004; Jones 2001). Organisations representing disabled people became fewer in number as the contracting model of health and care increasingly favoured large providers and cutbacks in everyday support services led to disabled people having to direct their energies towards fighting for their own services, often leaving little time for wider activism (Beresford 2013).

The dual forces of markets and managerialism (Harris 2003) were used by a succession of neoliberal governments post 1979 to reshape the role of the state with regard to its provision of health and social work. Dominelli (2004) argued that globalisation is a socio-political and economic form of social organisation which has penetrated everyday life all over the world, including aspects previously deemed sacrosanct and invulnerable to commodification. It has subjected public services to market disciplines and to what she sees as a reification of human relationships at the interpersonal level, disabled people perhaps being particularly affected by this de-valuing of relational ways of working. Under globalisation, peoples' allegiances to particular communities are dynamic and change is an ever-present factor. Traditional community ties are often replaced with less stable and more precarious bonds, and the globalised workplace is similarly characterised by short-term and fluid jobs (Dominelli 2004) which particularly disadvantage disabled people.



Short-term jobs and the increasing use of agency staff have risen steeply in recent years across health services, social care and social work, to the detriment of disabled people and their carers (Unwin 2009). Contemporary social work in particular is characterised by high vacancy rates and low morale, with complaints being universally made by social workers that they are overworked and overwhelmed with procedural tasks that afford little time for reflection and the building of relationships with users of services (Harris and Unwin 2009). Successive governments have failed to act on the recommendations of reports they commissioned such as the Social Work Reform Board (2010) and The Munro Report (Munro 2011). These reports made suggestions for dealing with excessively high caseloads and poor working conditions and argued for a return to relationship-based practice (Howe 2004; Ruch 2010) wherein social workers listened to, and acted upon, the voices of service users and carers (SUACs). Governments send mixed messages to the social work profession, based on ideology rather than evidence – variously that it is a ‘noble profession’ (Guardian 2013) or accusing social workers of abdicating responsibility. For example, Michael Gove (then Secretary for Education and Health in the Coalition Government) stated: ‘Instead of working with individuals to get them to recognise harmful patterns of behaviour, and improve their own lives, some social workers acquiesce in or make excuses for these wrong choices’ (Gove 2013). Implicit in such government-level criticism is that disabled people are responsible for their own situations and that professionals collude with such a status quo, not that any evidence was produced to support Gove’s claim.



Ruch (2010) and Howe (2014) argue that the key to improvements in social work lies in the nature of relationship between social worker and client, relationship-based practice having waned from the early days of casework due to the dominance of proceduralism and performance management systems imported from the world of business (Harris and Unwin 2009). If social workers do not have the time to develop relationships with individuals and their families, then decisions and judgements concerning disabled people are likely to be impaired because individual complexities are such that superficial relationships will not get beyond the surface of any presenting problem(s).

These ambivalent governmental messages are at odds with the various Codes of Practice that characterise the health and social work professions. The British Association of Social Workers (2014) Code of Ethics for Social Work is clear that discriminatory practice should be challenged, and the Nursing and Midwifery Council (2016) Code of Practice also places emphasis on non-discriminatory and individualised principles of practice. Students signing up for professional training courses across health and social work often demonstrate aspirations to work in such ways, even if they have had limited exposure to issues such as disability in their backgrounds. However, as Carey (2003, 126) reflects, such aspirations can become relegated to ‘mere fantasy in view of the daily grind in the office’.



Social work and health care education can also find itself at odds with the day-to-day realities of the world of practice because the curriculum has become

increasingly regulated by neoliberal governments since the 1990s, government drivers primarily being the need to constrain costs. Political interest in the potential of the SUAC voice to shape services from a consumer perspective first appeared in the NHS and Community Care Act 1990 and became recommended by the English National Training Board in 1996 in respect of the qualifying training of nurses in 1996. SUAC involvement in the qualifying training of social workers became mandatory in 2002 (Department of Health 2002). However, the extent to which universities providing professional social work training have embraced the involvement of SUACs in meaningful ways is open to debate and recent 'fast track' field-based social work training initiatives such as 'Frontline'(Maxwell et al. 2016) and 'Think Ahead' (Clifton and Thorley 2014) have paid scant attention to the SUAC voice. The potential to embed the SUAC voice from the beginning of professional training can underline to students that the people with whom they work are human beings first and foremost, and also provides opportunities for SUACs to flourish and develop skills in a learning and teaching environment not previously available to them. The benefits of such involvement may promote new perspectives in both students and SUACs, the former of whom may see the people with whom they will be working in positive, educative roles whereas the latter can gain new skills, insight and knowledge into how services should be delivered. Such skills might even be taken back to the organisations represented by participating SUACs and hence further bring about change and better promote practice, while students will hopefully take any new and positive insights into the world of qualified practice.

### Literature on SUAC involvement

There is a growing body of international literature regarding the role, purpose and effectiveness of SUAC involvement in higher education (HE) across social work and related caring professional courses such as nursing (for example, Anghel and Ramon [2009] in England; Towle et al. [2010] in Canada; Schneebeli et al. [2010] in New Zealand). However, little consensus exists about the benefits of SUAC involvement for students and little attention has been given to how such involvement might affect the lives of the SUACs. User-led groups have contributed to the literature in this area. For example, Advocacy in Action, Clarke, and Evans (2006) reported that social work lecturers appreciated the challenges and opportunities of service user-led involvement which was seen to positively alter students' skills, values and assumptions about disabled people. Branfield, Beresford, and Levin (2007) reported the findings of a joint project between Shaping Our Lives, the Department of Health and the Social Care Institute for Excellence which summarised the difficulties that service users encountered in becoming meaningfully involved with social work education. A compelling case was made for investment in user-led organisations if a wider representation of disabled people and others was ever to be achieved. Such investment did not materialise, however, despite limited funding being made available to help universities support SUAC involvement.



The majority of subsequent projects and literature on the issue of SUAC involvement have been from academic sources, which are discussed **in the following**.

Little evidence of systematic progress regarding SUAC involvement or evaluation of SUAC initiatives **in** HE were noted by Wallcraft, Fleischmann, and Schofield (2012) and by McCutcheon and Gormley (2014). Robinson and Webber (2013), in a specific study concerning social work training, concluded that there was little evidence **for** the effect of SUAC involvement on learners. However, Anghel and Ramon (2009) found evidence of strong partnership working between academic staff and SUACs which had led to perceived benefits for students. Brett et al's (2014) systematic review of publications in the SUAC sphere concluded that there was little evidence to support any claims for effectiveness with regard to SUAC involvement in student education, largely because of a lack of clarity in the papers reviewed regarding the nature and extent of this involvement. **With** regard to effect on SUAC participants, McKeown et al. (2012) found some evidence that SUAC participants did experience personal growth and benefitted from a wider social network of peers engaged in valued activity. Rhodes (2012) **concluded** that more research is needed before conclusions can be drawn about the **overall** effectiveness of SUAC involvement. None of the **mentioned** literature has been specific regarding whether the involvement of SUACs in HE training of health and social work students played any part in changing attitudes toward disability.

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### The research projects

The University of Worcester has its own SUAC group, IMPACT, made up of approximately **30** people whose backgrounds are primarily those of physical disability and mental ill health. They are remunerated for their input and undergo training in classroom presentation and basic research methods. The **u**niversity invests in systemic involvement of SUACs from interview stage through to classroom delivery and **in** carrying out research activities, partly with a view to producing outcomes whereby students hold positive images of SUACs to carry forward into practice. To determine whether there was any evidence of such outcomes at the University of Worcester, two small-scale qualitative research projects were designed and co-produced (Bovaird 2007) by IMPACT members, an undergraduate student and an academic, these projects respectively seeking to explore the effect of such involvement on the perspectives of students and SUACs regarding SUAC involvement in learning and teaching activities.

AO16  


Ethical approvals for the two research projects were given by the Ethics Committee of the Institute of Health and Society at the University of Worcester. The first of the two research projects into the effects of SUAC involvement on attitudes and practice involved carrying out focus groups with a total of 22 students (18 female, **four** male) from the following courses: **Master's** in Social Work ( $n = 8$ ), BA Honours **in** Social Welfare ( $n = 8$ ) and BA Honours in Mental Health Nursing ( $n = 6$ ). Volunteers had been sought by way of open invitation among the

student body for participation in these audio-recorded groups which were scheduled to take place out of timetabled activities. Focus groups were chosen **because** they were convenient and encouraged the free flow of ideas in explorative areas (Krueger and Casey 2009). The IMPACT researcher led the focus groups and the academic staff member worked alongside the IMPACT researcher and student team member in the study design, analysis and write-up. The focus groups explored questions regarding perceptions relating to having experienced SUAC involvement in the classroom; any follow-through effect on actual practice and ideas **were** sought regarding how SUACs might most effectively be deployed in the classroom in future. The academic member was known to the student applicants as a tutor and the bias that may have arisen from this pre-existing relationship led to his not being involved in the actual fieldwork and not having knowledge of the identities of participants. The second research project was concerned with exploring whether involvement in health care and social work education had made any difference to the lives, values and attitudes of IMPACT members regarding their own self-image and potential. An open invite was sent out to all IMPACT members, resulting in **15** members (11 female, **four** male) coming forward as participants. The methodology consisted of Skype telephone interviews being undertaken by peer IMPACT researchers with the academic staff member again being involved alongside the IMPACT researchers in the study design, analysis and write-up. For similar reasons of familiarity and power imbalance outlined **earlier**, the academic staff member did not participate in the fieldwork **but** the peer researchers did know several of their respondents which may have influenced some responses, although the depth of their **resultant** responses **suggests** that perhaps little was held back. Peer researchers were briefed closely in previous training about boundary issues and had ready access to their academic colleague to discuss any areas of concern had these arisen. The use of Skype telephoning made for flexibility regarding timings of interviews which also meant participants did not have to travel or change any care arrangements. Semi-structured questions were used exploring whether any benefits were perceived from involvement at the **university** **and** whether there were any perceived benefits that might have had an effect on the wider community; for example, through the passing on of skills and knowledge to other groups. Perceptions regarding barriers to participation were also explored and suggestions sought for improving levels and types of participation.


Findings **from** the student focus groups were synthesised into key themes around values and beliefs and seem to indicate considerable changes in attitude towards SUACs and disability, even if there was little evidence of transformational change. Three emergent themes were those of 'Empathy', 'Seeing SUACs as Real' and 'Challenging Stigma', all of which can be seen to humanise SUACs as fellow citizens rather than as some kind of underserving sub-class. In terms of 'Empathy', the following quotes are illuminative:



... instead of just seeing them as a patient or service user, you see them more as a person, and you try and look at things from how they might perceive it as well as what you have to do, so you can be more empathetic and try and provide better care.

I think it makes you remember that you're dealing with people as individuals, rather than just the service user umbrella. Because they've all been different individuals, they're just people, like we're all different people.

I suppose for me it's highlighted the importance of the relationship-based practice, and the fact that you are dealing with individual people all the time and you need to be able to get to know those people to find out what makes an individual, what their needs are.

10  These student respondents seem aware that SUACs can be presented as homogeneous in policy and practice rather than as unique individuals, and the shared humanity between professionals and SUACs is also appreciated and linked to relationship-based practice. Exposure to SUACs in a systematic manner across a professional education journey can hopefully also lay the ground for a return to relationship-based practice, argued by Ruch (2010) and Howe (2014) to be the key to meaningful and effective work across health and social work. Links with academic learning are further developed in the second theme – 'Seeing SUACs as Real'. The following quotes suggest that individuals are given positive attributes by students and that the effect of government policies on individual lives is brought into sharp contrast:

20 When you're in the university setting you can get a bit bogged down by the academia side of things. And it's nice to get back to hearing people's voices and remembering what it's about.

We've had quite a few people that have come in and said this service is really good, and then at the same time we've had people that have had negative experiences. So it's good because it gets you to think of it from different aspects as well.

25 It makes the academic work real as well I find, so you can go off and research and then go oh yeah that links up with what carer A said or carer B said. So it makes it real, which I like, so you can work together.

The third stream of relevance to issues of disability perception in students is that of 'Challenging Stigma', this theme illustrating an increase in self-awareness about prejudice that can be carried even by those entering a caring profession. Several students reported reflecting on prejudices previously held as a result of classroom exposure to individuals from a range of background disabilities, both physical and mental:

35 ... he has acquired disability ... and from what he was saying he has managed to have a good life for himself really by challenging the system and being able to be vocal on so many things and have that last say of what he wants in life. And somehow he gets to be listened to, and for him to be able to get to the extent of being able to come and talk in class is a massive achievement in my point of view.

40 We hear what the lecturer is telling us and we read the books and do the research, but by having a one-to-one with service users in front of you in the classroom it's very good.

So it's more the fact that it promotes recovery I suppose, which is a big thing in mental health, and it shows that we can help people to get better no matter how ill they were,

are or how many times they've been ill, how many times they've been in the services, there's still hope, which is very good.

The second research study into the experiences of SUACs who were involved across the spectrum of interviewing students, delivering classroom sessions, assessing work and carrying out research was designed to elicit views about self-perceptions of the value of such work, an area little explored in the literature. Findings were again analysed **thematically** and, in contrast **to** the nature of student responses in the **first** study, significant reports emerged stating that IMPACT members' lives had been transformed by their involvement in HE. The key question asked in this project was 'Do you think that being an IMPACT member has changed your life in any way and if so how?' Answers were themed in **the** terms of 'Personal Impact' ( $n = 7$ ), 'Social Impact' ( $n = 14$ ) and 'Work-Related Effect' ( $n = 3$ ). Examples of these themes are given are **in the following**, beginning with 'Personal Impact':



I feel it has given me a radical, more positive outlook on life ... **it's** given me a broader view about what potential there is for me to make a contributions.

I think it has changed my life ... I've certainly got a contribution I can make in the training and formation of professionals who may be looking after me or my son in the future.

I've been able to regain my confidence. There are several other skills you could lack as well when you're a carer sometimes, essential activity is key.

These **quotes** suggest significant personal change in terms of self-esteem and acknowledgement of the value brought to student experience, with some acknowledgement also that the work is undertaken partly for the benefit of others in the future. The **following** **quotes** in respect of the second theme 'Social Impact' suggest that a significant community has been created via IMPACT, one in which people care **for** and support others. Contact outside **formal** university sessions and meetings was **part** of IMPACT membership for several people, close friendships having been formed and 'buddying' systems having developed whereby more experienced members helped new members develop skills and confidence across a range of tasks:

I think it has changed my life ... from the point of view of having met people that otherwise I would not have met, understanding people's points of view and getting richness from that experience.

Probably in the way that you are not alone ... **and** talking and sharing experiences ... **it's** like a supportive group so when we touch upon topics that to some bring up bad memories, or they'd struggle in some way, but we were there to offer support to each other, which is good.

IMPACT has actually given me an opportunity to have new friends who are all with different backgrounds and have different abilities, different strengths and weaknesses, but we all have a common goal, and it's given me a better quality, more meaningful life to be honest.

So you've got social networking with people and speaking again and sharing ideas and thoughts is great. And just purely feeling valued as well.



Several people have made me feel wanted. You know, it's brilliant that people make you feel you are just more than an old bloke in a wheelchair.

The third theme, 'Work-Related Effect', was an unexpected theme to emerge and one which is new to the literature. This theme recognised growth in confidence and self-esteem in SUACs who participate in professional training courses at HE (for example, McKeown et al. 2012), but have not made any links with progression into work roles:

It's given me the opportunity to get back into paid employment which feels manageable, given my health challenges.

I've enjoyed doing and actually getting paid for it, whereas a lot of the things I do are for free. So yeah, it's been helpful.

It's helped me to become a more confident person, to believe in myself and to know you know. I wasn't working when I started at IMPACT. And I think being a part of IMPACT has actually helped me to get the job that I'm working in now. Because ... it just helps me in a lot of ways and everybody, it just helps me to believe in myself, and that I'm not alone, it's lovely.

## Discussion and conclusions

Both projects were small scale and qualitative in nature but nonetheless provide insights which largely view SUAC involvement as a meaningful activity with some elements of it being transformative, especially in the perceptions and life changes that were reported by SUAC participants across a variety of backgrounds and disabilities. Such findings are in line with the findings of Anghel and Ramon (2009) and McKeown et al. (2012), and contrast with some of the literature (for example, McCutcheon and Gormley 2014; Wallcraft, Fleischmann, and Schofield 2012) which is ambivalent about the meaningfulness of SUAC involvement in HE. The focus on exploring SUAC values and attitudes and how they might affect participants' perceptions about their own disability and potential was a rather novel one in terms of the existing SUAC literature, most of which (for example, Brett et al. 2014; Towle et al. 2010) has concentrated on the effects on students and has not considered the effects on SUACs and their potential to develop personally as a result of such involvement. IMPACT members have clearly experienced significant transformations themselves as a result of participation and these findings together can be seen to make out a case that SUAC inclusion can indeed make a tangible contribution towards the promotion of positive models of disability, both in SUAC participants and in the student body.

The findings from IMPACT participants were interesting in their perceptions that their HE roles have had such considerable additional benefits in terms of self-esteem, skills and friendships. This finding, albeit from a small-scale study, suggests that such involvement can even act as a springboard to employment and represents a new contribution to the literature. Further research into the benefits



for disabled people becoming involved with the professional training of health and social work professionals is recommended.

Several students in the focus groups experienced SUAC input as meaningful, even if not transformative, in the dispelling of myths and in seeing disability in its unique and individualised forms, and it is to be hoped that such positive perspectives will be carried through to their professional health and social work practice worlds, currently dominated by business models that do not value relationships (Harris and Unwin 2009). The response across both research projects might be seen as helping make real the aspirations of Codes of Practice such as those of **British Association of Social Workers** (2016). The findings, although evidencing some of Söder's (1990) ambivalence in attitudes towards disability, suggested that students viewed IMPACT contributors as people first who might be conceptualised as equals rather than as the units and cost centres of the contemporary health and social care business cultures they are about to enter (Harris and Unwin 2009). Further research is recommended into this key question of whether the values and attitudes influenced by meeting SUACs as a core part of an educational journey are carried through to qualified practice.

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