



**Service user and carer representation: exploring barriers to participation**

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Figure: [Unsplash](#)

## Introduction

[UNITY](#) is the University of Stirling service user and carers' (SUAC) social work involvement group. UNITY has been established for over 10 years and members contribute to the design and delivery of the qualifying social work programmes and more recently have contributed to the Nursing programmes. In this article the term service user refers to people who have or continue to use health and social care services; carers refer to people who carry out a caring role for family members or friends in an unpaid capacity currently or formerly.

At a UNITY meeting, it was striking to hear that numerous members had left their local user and carer participation groups, in third sector and public sector health and social care organisations after several years of input. This realisation led to a number of UNITY members coming together to write this article to explore barriers and good practice for service user and carer involvement by drawing upon examples from social work education, research and practice.

## The importance of service user and carer involvement

SUAC engagement in education, research, policy and practice at best is meaningful and effective and can result in significant change that benefit recipients of social work services. Consultation practices are not a new phenomenon. A decade ago, the [Changing Lives](#) report provided a review of social work services and outlined some of the mechanisms to facilitate successful participation, stating that *"People who use services can be both inspirational and visionary"*. Scottish Local Authorities, [Community Planning Partnerships](#) and Health Boards are required to consult with users and carers via consultation groups and [patient and public involvement](#) engagement. The Public Bodies (Joint Working) Scotland Act 2014 places a requirement on Local Authorities to include a Carer Representative on their Integrated Joint Board and the Carers (Scotland) Act extends carer engagement to other areas of health and social care planning not covered in the Public Bodies Act.

In Social Work education, SUAC involvement is a requirement of the Scottish Social Services Council (SSSC) and provides essential knowledge, insight and perspective for social work graduates that informs their preparation for practice. Public involvement is also commonplace in research. UK [Research Councils](#) require academics to identify and actively engage relevant users of research; to articulate a clear understanding of the context and needs of users and to consider ways for the proposed research to meet these needs.

The process and output of SUAC involvement can be innovative and meaningful in education, research, practice and policy making. Through participation, SUAC represent members of the community who may be sidelined and neglected. SUAC involvement can challenge hierarchical structures and ideas about expertise, re-positioning the position of service user/carer's as 'experts'. SUAC involvement has resulted in changes and development to practice and policy. For example, designing new models of care, improving accessibility and feedback mechanisms, creating easy read pamphlets for patients and general contributions to engender greater choice and control over services.

### **Service user and carer involvement in social work education**

SUAC in social work education across the UK varies between institutions. One of the underpinning learning objectives for SUAC in education is for students to hear directly from service users and carers about their reasons for being involved with social work services and for students to critically reflect upon this learning and the implications for practice. Involvement may include delivering and designing activities, chairing meetings, interviewing social work applicants, planning and presenting at conferences, contributing to university policies and strategies, contributing to commissioning panels, supporting consultations, improving governance, assisting inspections and contributing to research, amongst other activities.

SUAC is essential, not only for the validation of social work education, but to ensure that future social workers learn directly from users' experiences and perspectives of using social work services, acknowledging difficulties as well as the positive experiences and outcomes. SUAC teaching input can be exciting and powerful and result in shifts in perceptions and lasting messages for both students and academics. The format of input can vary between individuals, some people skillfully use humour and 'storytelling' to talk about life experiences, other people

are quieter and prefer one-to-one or smaller group discussion. Student feedback about UNITY input at the University of Stirling is overwhelmingly positive and forms an important part of the student learning experience. In end of programme evaluations, final year social work students have attributed key practice messages to their engagement with UNITY members during the programme. For example, practising with respect and dignity, communicating clearly, timekeeping, and expressing empathy.

Student feedback repeatedly indicates that hearing directly from UNITY members experiences motivates them to be '*the best social workers they can be*' and this chimes with their professional development, to become critically reflective practitioners. One of the interesting outcomes of SUAC input is the role-reversal that can emerge; with UNITY members exercising their compassion for students following student: SUAC interaction. Members are aware that students may find the content and process of listening to UNITY members' problematic and challenging stories can arouse student's own difficult feelings and experiences as service users or carers and/or difficult times for their lives. Members have been seen to offer verbal advice to students; encouraging them to exercise self-care and signposting them for further support at the University. The role-reversal of caring interactions between SUAC and students reflects the underlying humanistic element of social work; that any one of us may need to use social work services and that care and compassion are fundamental human qualities that are important to all of us, no matter who is deemed to be the 'expert'.

As well as benefitting the academy and social work profession, SUAC contributions in education have been found to be beneficial to members themselves. One UNITY member said the confidence he gained from teaching input and conference presentations enabled him to apply for a job. Another member talked about the therapeutic benefit of talking about her experiences of using mental health services, as she reflected on a '*dark period*' of her life. She was hopeful that students would learn from her negative experiences and use this experiential knowledge to shape their practice.

In pedagogy, research and practice, SUAC involvement can be challenging and problematic, as researchers (Beresford et al., 2012<sup>1</sup>; Hitchin, 2016<sup>2</sup>; Lucas and Thomas, forthcoming<sup>3</sup>) have

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<sup>1</sup> Beresford P., Wallcraft J., Schrank B., Amering M (2009). User-controlled research, Handbook of service user involvement in mental health research, Chichester: John Wiley.

argued. There is concern that involvement can be tokenistic and this concern was shared by UNITY members. SUAC and students may feel nervous about talking with one another and feel potentially exposed and vulnerable. It is possible that recalling life experiences may trigger difficult, painful memories and student social workers may not be adequately skilled and resourced to engage or listen to SUAC. This experience may be uncomfortable for both the student and UNITY member.

Despite the huge range of contributions that SUAC offer there remain concerns about the University's capacity to satisfactorily recognise the contributions that SUAC make. Adequate resourcing, accessible parking, rooms and distance between preparation and teaching rooms are important to consider and these issues need to be addressed to enable participation. The issue of whether or not to pay SUAC for their input remains a matter of contention. There are different practices amongst Universities and different opinions expressed by members – some do not want to be paid as this may change the expectations of their involvement, other members have expressed that payment by bank transfer could be problematic as it can affect benefit payment. At the least, SUAC in all Scottish universities are reimbursed for their travel and refreshments are provided at meetings and after teaching. Additional costs besides money for member's input could be remunerating carer's time and providing cash expenses on the day, rather than leaving members out of pocket by later reimbursing expenses by bank transfer.

### **Unreasonable expectations in practice?**

Despite the Public Bodies (Joint Working) Scotland Act 2014, and the requirement to consult with people who use services, there is no consensus about what this should look like in practice. The 'Equal, Expert and Valued' report (Coalition of Carers in Scotland, 2017), found common pitfalls in carer representation. Overall there was concern that there were no clear mechanisms in place to determine what changes or development resulted following SUAC involvement. This included not being listened to and inadequate structures for inclusion and representation. The '[Equal, Expert and Valued' report](#) (2017) indicates that barriers to involvement include long or unfocused, fast-paced meetings; overly-full agendas; little opportunity to input, influence or contribute to agendas; and an emphasis on process rather than outcomes and actions. These experiences have

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<sup>2</sup> Hitchin, S., 2016. Role-played interviews with service users in preparation for social work practice: exploring students' and service users' experience of co-produced workshops. *Social Work Education*. 35, 970–981.

<sup>3</sup> Lucas, S.E., Thomas, N (under review) Listening to care experienced young people and creating audio-bites for social work education.

been echoed amongst UNITY members in regards to their involvement with external agencies and contributed to their reasons for leaving various consultation groups.

*“Service users are the least informed going to any meeting” [UNITY member]*

UNITY members reported that it could be difficult to contribute to consultation meetings with professionals. Papers were not always circulated in advance and meetings were filled with jargon. In reference to involvement at a Health Board, a member said a 3 page glossary of terminology and acronyms was circulated at the start of the meeting and attendees were expected to refer to this document throughout. No attempt was made by the professionals to use full expressions and this made the meeting difficult to follow and restricted participation:

*“...you were expected to refer to the glossary and catch up, and you felt a little daft” [UNITY member]*

### **Working together**

Intimidation can be symbolic and explicit, in the sense of professionals exercising their authority as experts and positioning the SUAC as subordinate. Discrimination can engender an ‘*us versus them*’ orientation and can be subtle; felt but not easily discerned, for example feeling unwelcome and inferior to professionals. Discrimination can also be overt - UNITY members reported attending SUAC conferences as invited delegates, but name badges were only provided to academics and agency professionals.

*“...at a patient liaison meeting for mental health services, a Consultant announced that **he** was in charge and was not there to listen to other people’s views” [UNITY member]*

*“Some professionals deliberately intimidate you” [UNITY member]*

One UNITY member’s response to challenge a Doctor’s ambiguity was to respond using a deliberately made-up phrase: *“Well Doctor, I think what you are saying is ‘intrinsically arabotious’”*. The intentional use of a fabricated phrase made the Doctor pause, slow down and reflect upon his use of language, realising he was not speaking clearly. Without the individual having the confidence (and wit) to challenge this professional there was the possibility that

important information would be missed. The UNITY member therefore highlighted inaccessible language practices and showed the importance of using [‘Plain language’](#) to communicate clearly and effectively.

### **The glass ceiling effect**

One UNITY member reflected on his different consultation roles in public sector organisations. For a period he felt connected to the agency and respected as a colleague. Positive working practices took place that made him feel valued. For example, knowledge of key people in the agency and staff and policy and procedure changes. However, a change to the location of consultation group’s meeting room meant that it became harder for the group to maintain relationships and presence in the agency and consequently their involvement became sidelined. The UNITY member decided to leave the group after increasingly feeling that despite attending and contributing to planning and strategic committees his views were not respected, and there was no evidence to suggest that his input was affecting change. This uncertainty related to queries about traceability; whether SUAC input is taken on board, as one UNITY member commented:

*“I wonder what happened to that DVD where I talked about a really difficult time of my life, it was meant to be distributed but never was”*

Meaningful involvement with SUAC requires time, relationship building, planning and resource. The act of listening is an important communication skill and all professionals should practice patience and respect, this is illustrated with reference to ‘Alice’ (pseudonym used), a member who needs time and patience to express her ideas.

*“Take Alice, who goes off at tangents when she’s telling you things. She explains by saying that her mother’s brothers, blah blah blah and you think...‘where is this taking me?’ and you’re thinking, ‘hurry up and get to the point’. But....if you just listen and let her go at her own speed, you realise that she’s got some really brilliant ideas” [UNITY member]*

SUAC’s voices may be listened to, but not *heard* and taken on board. One UNITY member felt that rhetoric claiming to allow ‘free expression’ could be problematic for SUAC if his or her views did

not align with the professionals, and in such cases, they may be constructed as a threat rather than a help. Disagreement and differences of opinion occur in all meetings and may be missed from formal records, meaning that one version of truth is presented rather than a variety of perspectives. The professional often has the final say on matters and constructs him or herself as 'the expert'. A member likened this to the '*glass-ceiling effect*' in the recognition that his involvement was important but limited, as it could only contribute so far.

## Conclusion

There are a number of pitfalls that limit meaningful and effective SUAC involvement. SUAC need support to become better connected with the organisations they work with. These organisations need to ensure that involvement is not tokenistic, that accurate recording occurs and feedback mechanisms exist in which members see the outputs or are informed of the impact (short or anticipated) of their contributions. Finally, it is important not to homogenize SUAC's experience with consultation groups. There exist many positive examples of engagement and attention from staff to facilitate meaningful involvement and UNITY is a positive example of meaningful SUAC involvement (cf. Clarke 2014<sup>4</sup>).

N/B: This article draws upon the view of individuals, not necessarily all UNITY members nor those of the University.

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<sup>4</sup> Clarke, J (2014) Unity Abounds! *Division of Clinical Psychology, Scotland*, 11., 24-28. Available: <http://www.chrysm-associates.co.uk/images/dcpscotlandreview.pdf> (Accessed 1-08-2019).