**Improving Understanding of Service User Involvement and Identity:**

**Collaborative research traversing Disability, Activism and the Academy**

**Abstract**

This paper focuses on collaborative research traversing disability, activism and the academy to improve understanding of service-user involvement and identity. The project was undertaken by an organisation of disabled people, some of whom are, and some who are not, employed by academic institutions. It is an example of research fusion between disabled people’s activism and their work within the academy. The project aimed to identify meaningful ways of promoting involvement in the development of public services. Power relationships which shape the reality of disabled people’s participation in decision-making processes within services are critiqued. We explore ways in which disabled service users and our representative organisations can drive a form of political activism within services and through the academy to improve the lives of disabled people according to the priorities of disabled people themselves. This is not simply an academic project; we identify strategies for activism and change.

**Points of Interest**

* Our project looked at disabled people’s views about their experiences trying to improve services they use
* Disabled people carried out interviews with other disabled people about their involvement in trying to get services changed
* When disabled people are treated with respect they can play a valuable part in improving services
* Service providers need to pay more careful attention to proper inclusion of disabled people in discussions about services and how to improve them
* Practical ideas on how service providers can involve disabled service users are given

**Improving Understanding of Disabled People’s Service User Involvement and Identity: a collaborative activist project to shift the power and impact of research**

**Key words:** Disability, research, access, service users, user-led research, Disabled People’s Organisations, participation

**Introduction**

In this article we discuss a project which aimed to utilise a strong relationship between disabled people, the academy and service user activism in order to improve understanding of what is involved when disabled people engage in service user involvement. We were also interested in how the experience of being a service user representative can impact on identity. The central goal of the research relates to how to strengthen participation –or ‘representative’ action– by service users within services. The project was undertaken by an organisation of disabled people called Shaping Our Lives ([www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)) a leading UK think tank, some of whose members are, and some of whom are not, disabled people employed by academic institutions and, as such, is an example of fusion between activism and the academy. The work we carried out gives an example of disability research with an explicitly activist agenda which set out to identify meaningful ways of promoting inclusion of disabled people in the development of public services. Of course this mix of identities and objectives happens both within other research led by Disabled People’s Organisations and in academic research where disabled academics are prominent players, and also in what is termed ‘inclusive research’.

Awareness that disabled people and their organisations should be in control of research has been in place for decades, since Zarb’s assessment of research commissioned by organisations of disabled people and other work carried out within a framework of ‘user's perspectives’ on services and policy (Zarb, 1992). The research which is the focus of this paper takes a fresh look at power relationships in the dynamics of service user representation and critiques the reality of the participation of disabled people in decision-making processes within these services. We have focussed on disabled people’s experiences of being service user representatives, and on thoughts about our involvement as ‘service user experts’ in service and policy development. The research at the centre of this paper is wholly user-led; conceived, designed, carried out, analysed, written up and disseminated by disabled service users.

From the very beginning, our project was developed to critique professional perspectives and as an attempt to bring to light the views of disabled people about their own experiences as service-user representatives. The focus arose directly out of the concerns of the late Patricia Chambers, a disabled woman who expressed deep concern about how her experience as a service user–representative was routinely rendered semi-visible or semi-acknowledged within normative discourses. Patricia pointed out that many disabled people have regular experience of being asked as ‘service user experts’ for our views. Within these consultations, it appears as if what we have to say is valued and taken seriously. But back in the context of day-to-day experience, a service user's status or identity as an ‘expert’ advisor to service providers is forgotten and less respectful power relations resume. Role conflict and role ambiguity is experienced which can leave service users confused over status and concerned about having been used or exploited.This issue was discussed more broadly by members of Shaping Our Lives because Patricia’s reflections on her experience of being a service user representative resonated with us all. It emerged that in our various roles as service user representatives many of us experience being un-acknowledged and marginalised; left with uncertainty about the extent to which our experience is really considered important or likely to make a difference. Subsequently we as disabled people, although ostensibly being included as service user representatives, remain in the ‘half shadows’ – being known to exist, asked to inform service planning and delivery, but not being acknowledged or included as equals either within, or outside of, this role (Cameron et al, in press). Many of these issues have been discussed elsewhere. For instance, the participation of people with intellectual disabilities has been particularly critiqued (Redley and Weinberg, 2007; Williams 2013), while a series of reviews for SCIE around 2004 onwards included the views of disabled people on their ‘participation’ in direct ways, showing some of the same conflicts we are concerned with. More recently, research with Disability Rights UK has also found that service users can have some very mixed reactions to involvement with local authorities.

We therefore decided, as a group of disabled service users with shared experience of being marginalised and insufficiently acknowledged, in our role as service user representatives, to set up research to explore the extent of our rendition to the half-shadows and to work out strategies for bringing our experience in to the light. This paper reports on that project, casting light on how far the aspiration to bridge the gap between the academy and activists in the disability arena has been realised within services we use.

Our work responds to our individual and collective experience of being involved as service user representatives in forums where service providers acknowledge the importance of bringing our experience out of obscurity, yet little attention is paid to the impact of this involvement on service users who give our time and energy to the role. For some of us it transpires, while inclusion as service user representatives is intended as a strategy to raise our seldom heard voices and involve us in planning and evolving services using our experiential knowledge in its construction, the experience can reinforce feelings of exclusion, diminishment and inequality. We wanted our research to explore ways in which as disabled service user representatives we feel our inclusion can be improved so that our input to service development, policy and practice is not marginalised or under-utilised but fully acknowledged, productive and personally rewarding.

Our research findings are oriented towards improving understanding of good, and conversely unsatisfactory, experiences of service user involvement in the commissioning, design, delivery and evaluation of public sector services. We consider the challenges faced by service users in negotiating our dual role of being both a service user representative and recipients of services from our own point of view.

Following the research we have been able to offer clear practice pointers on how to facilitate the process of service user representation to expand positive experience and outcomes for all. We have found that when service user involvement is respectful and inclusive this has mutually beneficial impact for professionals and service users alike. When arrangements for user involvement do not pay sufficient attention to dismantling barriers to participation, service user representatives experience organisational exclusion; we feel our contribution is not adequately respected and the experience of being involved as service user representatives recycles oppression.

***Shaping Our Lives***

Shaping Our Lives is a national organisation and network of user-led groups, service users and disabled people established in 1994. We are committed to inclusive involvement and specialise in research and the practice involving diverse communities in policy, planning and delivery of services. We have worked with health trusts, local authorities, in social work education, and with a broad spectrum of human service providers. Our inclusive approach means that irrespective of people’s impairments – whether these are physical, sensory, emotional or cognitive – everyone has an equal say within our work. Through our network of more than 430 user-led organisations Shaping Our Lives aims to improve the quality of care and support services people receive by:

* Enabling the inclusive involvement of service users and carers in policy, planning and service delivery nationally and locally so better outcomes are achieved for service users and carers.
* Educating through user-led research and service user perspectives on the cycle of services from planning to evaluation.
* Training professionals to be service user focused and to work inclusively with a diverse range of people and their carer givers.
* Giving a shared voice to user-controlled organisations and the people who take part in them.
* Enabling groups to link to other user-controlled groups by providing an equal and accessible network.

As a user-led organisation of disabled people, Shaping Our Lives values are underpinned by the social model of disability (Oliver, 1990; Oliver 2013). This involves making a distinction between impairment and disability: we recognise impairment as a limiting embodied condition or characteristic, and disability as the outcome of an unequal social relationship for people with impairments. Using this definition, disablement can be understood as an experience ‘imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society’ (UPIAS, 1976). Rather than viewing disability as a ‘problem’ to do with the bodies of individuals, we view disability as a matter of how society responds to, or has failed to respond to, the needs of people with impairments (Shaping Our Lives, 2014).

We see ourselves not as *‘people with disabilities’* but as people with impairments who are disabled by society to the extent that society imposes physical, social and cultural barriers as we try to negotiate everyday life (Clark, 2014). These barriers can range from inaccessible buildings and public environments to unwelcoming or complacent attitudes. Working with, and through the social model of disability, has an important implication for our work because it enables us to locate the need for change within institutional practices and behaviours which are inherently, if unintentionally, disabling. This theoretical approach informs all of our work and is foundational to our campaign to ensure that our experiences are taken seriously.

It is important to make the distinction between a social model approach and an individual model approach to understanding disability, because it is the latter which has traditionally shaped the way that services for disabled people have been organised and delivered. McKnight (2005) explained how the traditional relationship between professionals and service users has established the message that disabled people are ‘the problem’, that service providers have ‘the answer’, that disabled people cannot come up with ‘the answers’ to our own concerns and also that the resolution of our problems does not lie in the political, social and economic environment. Within Shaping Our Lives we refute all of these traditional assumptions which invalidate the role disabled people can play in determining our experience of services; our main focus is on the disabling aspects of society as a universal truth.

Despite considerable progress made in recent years in terms of service user-involvement, attention to ‘joint planning’, ‘co-production’ and other strategies intended to be inclusive and empowering of disabled people, at Shaping Our Lives we are still exercised by how long it takes for tangible change to the traditional relationship between service providers and service users described above to occur (Beresford, 2016; Beresford and Carr, 2018; McPherson and Beresford, 2019). In our discussions we find that we commonly identify much tokenism, condescension, and a feeling that organisations only consult with us as service users because they are obliged by good practice guidance rather than because they are committed to doing things differently. Through these conversations we identified the clear need to find out more about the experience of service users as service user representatives.

The social model thinking which runs through everything we do at Shaping Our Lives also determines the emancipatory principles which underlie our approach to research. Our research is always constructed using the social model of disability as the framework for our research production; we only do research where it will be of some practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers and we take ownership of research ourselves in order to ensure full accountability to disabled people and their organisations (for further discussion of the origins and significance of these principles see Cameron, 2014). These principles guided the formulation of the research project we decided to carry out building on the concerns of Patricia Chambers and evidencing the links between ideas established within Disability Studies and our own activism.

As a prominent member of the Black and Minority Ethnic mental health user/survivor movement in London, Patricia had talked at a Board Meeting about the sense of role conflict she felt in being treated on the one hand with respect – as an ‘expert by experience’ – when involved as a service user representative, seen as someone who had a potential contribution perceived as of value to service provider organisations wishing to engage her – and, on the other hand, outside those situations being relegated to ‘*just a service user’*  even by the same professionals who extracted expertise from her service user representation. Patricia observed a contradiction in the treatment she received from service providers with whom she had contact depending on whether she was ‘in’ or ‘out’ of the service user representation context; in and out of the half-light determined by whether she was being seen as a service user or a service user representative when, of course, she wished to be treated with equal respect and attributed the same value for being the same person that she was irrespective of the role or moment she was in. When she was involved as a service user representative Patricia observed a respectful formal acknowledgement by service providers of the need to listen to her perspective as key to the successful evaluation and development of services. Yet outside of the situations in which she was seen as a ‘service user representative’ she noticed the relationship between herself and those providers to whose consultations she had just contributed reverted to one characterised by inequality; *‘in the meetings they say ‘hello Patricia, how are you? But when they next see me on a corridor they act like they don’t know me’*.

We have described how Patricia’s observations were shared by many members of Shaping Our Livesand theseformed the kernel of our successful bid for research funding to the National Lottery Awards for All programme to find out more about the impact of service user representation on service users and to evolve ideas about how our involvement as service user representatives can be enhanced.

**Research approach**

By combining ideas from academic and non-academic activists in our organisation we set up a qualitative user-led project to find out:

* How does being a service user representative impact on service users?
* Are there conflicts between our experiences in everyday life and our experiences as service user representatives?
* What do disabled people feel could be done to minimise any conflicts and thus enhance the impact and significance of service user involvement?

Research participants were recruited through Shaping Our Lives network communications to over 470 user-led organisations across the UK, predominately in England. Our recruitment strategy asked for participants with more than one experience of being a service user representative and/or experience over a number of years.

Twenty-two disabled people, geographically distributed in the following areas: North East of England, East of England, London and South West, agreed to take part in in-depth face-to-face recorded interviews for the study. Each participant chose a comfortable place for the interview to suit them. In line with Shaping Our Lives policy on participation, each interviewee was offered an involvement payment and all associated travel and support costs were met.

Everyone interviewed had at least two examples of past representation roles and the majority were still actively involved as service user representatives. Approximately a quarter of the respondents had held five or more roles and the same proportion had held ten or more representative roles. One person listed over twenty different boards and service user advisory roles they contributed to. The types of representation participants had experience of ranged from Partnership Boards in local authorities, Patient Participant Groups in primary and secondary health care, roles in education and voluntary sector structures, advocacy and carer representative positions. There was also mention of involvement with local government structures such as Healthwatch, Clinical Commissioning Groups and Transport Advisory Committees. Half of the people taking part also mentioned a role they had with a local charity or user-group for disabled people.

***Profiles of Participants***

Of the twenty-two participants, twelve were women, nine were men and one person identified as non-binary. Age ranges varied with two participants being under 40 years old and two over 70 years old; the remaining participants were equally split between 41 and 55 years old, and 56 and 70 years old. There were no disabled people under 25 years old in the study. We made strenuous efforts to engage representatives of a hospital based youth service user group however the young people approached were busy with exam commitments and could not fit in interviews. It is also the case that people who take part in representation activities tend to be people who have had many years of using services as an adult. Those who took part had a broad range of impairments and health conditions. There were four people with varying degrees of sight loss including one person describing themselves as ‘totally blind’ and one deaf person. Among the other participants the following were used to describe our range of impairments and health conditions: acquired brain injury, cognitive impairment, learning disability, mental ill-health, non-epileptic seizures, Multiple Sclerosis, Cerebral Palsy, spinal injury, mobility impairment and two people who identified as wheelchair users and having poor mobility. One of the research participants was also a carer of four disabled children.

The data therefore introduces the voices of different groups of service users, starting from our personal experience of service user representation.

**Findings**

Each respondent’s interview was fully transcribed. A thematic approach was taken to analysis to interpret the data using principles of recurrence and repetition to elicit common points of interest and also paying attention to the importance interviewees themselves placed on particular issues so that the power of any particular view point was accounted for and outlying concerns and ideas were included in the picture of findings built up. In this way, critically informed themes could be purposefully selected and examined.

As will be shown, there are important questions to ask about the experience of participation or representative action by service users within services. For a variety of reasons that we will describe below, the hope to realise meaningful participation or representative action by service users within services is not necessarily met with success. Our data indicates identities can frequently become overridden, marginalised and conflicted. The body of our analysis is concerned to illustrate this and reflect on why this is often the case.

**Service Users have what it takes to shape services**

In relation to how being a service user representative impacts on service users themselves participants gave many different responses about how involvement and representation activities had made them feel including, most importantly, that being a service user representative can make us feel better about ourselves as service users. Positive responses suggest that being able to help improve policies and services for other service users was satisfying and rewarding including:

* Felt good to be listened to and make a difference
* Felt good to represent people who cannot represent themselves
* I could provide information to improve policies
* Gave me a purpose to help people and not just disabled people
* I felt empowered to talk about issues that affect people like me
* If it is with someone committed (to involving service users) it feels quite good
* An experience ‘I valued at the time’

However, there were more negative responses concerning the experience of service user involvement than positive. These comments can be viewed in categories of: process, i.e. the organisation and execution of the involvement activity; or personal difficulties experienced by service users working as representatives.

The poor experiences grouped as ‘process’ problems suggest a number of issues. Firstly, service user representation activities have no meaningful outcome if the process is inaccessible, inflexible, too long and/or tokenistic. Involvement is particularly unsatisfactory if the voices of the service user representatives are not being listened to or heard. Process issues, of course, relate to power imbalances between the professionals organising the activities and the service users taking part and were described as follows:

* Frustrating as it takes so long to make a difference
* Annoying as it became clear that it was a tick box exercise
* Difficult as there was a set pathway and you had to understand this to make a difference
* I felt patronised as they were not listening to what I had to say
* If it is someone not committed it is depressing, frustrating and head-bangingly annoying
* Pointless as they have their regular service users who get listened to more than others
* Service user input is always at the end of the agenda and the professionals start excusing themselves.
* Tokenistic and not acted on

It cannot be overlooked that there are also ‘personal’ conflicts and difficulties in taking part as a representative for service users and our findings suggest this may be because of the stress it puts on mental health; the general pressures of living with an impairment or health condition; the extensive knowledge needed to take part in some representation activities; sharing lived experiences with other people and sharing experiences with professionals responsible for the care of the representative. However, people who had had good experiences of being involved as service-user representatives had been able to overcome or manage these personal conflicts through supportive and inclusive processes: ‘*quite complex really, it was difficult but rewarding at the same time’ .*

‘Personal’ barriers to service user involvement mentioned include:

* Feeling apprehensive at speaking about an impairment or health condition I may know nothing about
* Difficult if a professional last saw you when you were receiving treatment
* It can be difficult to listen to other people’s experiences
* Difficult as people do not give me time to speak (person with a speech impairment)
* Drawing on personal experiences can be distressing and exhausting.

Respondents also talked about a sense of responsibility and skills needed to speak on behalf of a wide range of service users if this was part of the requirement. One person reflected that it was easy to be a passive recipient of a consultation, but to speak and effect change on behalf of others required you to advocate, critically assess the impact of changes, make clear references in presenting an objection and to be able to think on your feet. Another person talked about needing to grow into a role, listen to what other people had to say and not back people into a corner as this would make discussions difficult.

When asked about how being a service user representative had been a good experience, many benefits of social connection were described:

* Good to be part of a team
* Involvement gave me a sense of purpose
* A feeling of being wanted and needed
* I felt that my knowledge and experience was valuable
* I was motivated and excited when the contribution I made was acknowledged
* Good when it made a difference, there can be a feeling of being stronger through effecting social change.

A number of essential ingredients for a good experience of being a service user representative were identified:

* Equality
* Mutual respect
* Ownership
* Structure
* Commitment
* Feedback
* Personal development.

Quotations from the interviews have the potential to show more deeply some of the meaning behind these observations and we draw out further commentary through longer quotes next.

**How service providers can support service users in shaping services (or undermine involvement)**

Opportunity for personal development through service user involvement was described in many different ways including participation in training, acquiring new skills, gaining knowledge, opportunity for paid or voluntary work, increased confidence, opportunity to network/make new friends, increased self-worth and finding out about services and organisations in the area. Several people pointed to the importance of opportunities for personal development for a positive experience, for example:

*“I think the best one for me used to be the Partnership Board because they had a mentoring system and I was getting some training that helped me be a representative.”*

Where service providers do not adequately address both personal and practical issues of inclusive involvement, the process of inclusive communications and attitudes is likely to be less enabling for service user representatives. One person said they would have welcomed the opportunity to sit down and talk about what the ‘professionals’ were trying to achieve, how they were planning to do it and what would be involved before agreeing to become a representative. This would help reduce or even eliminate practical process issues such as finding oneself not being sufficiently supported with access arrangements; we heard many reports of service users being ready to join meetings only to find practicalities such as travel arrangements and parking had not been arranged.

Results further indicate that communication issues are not consistently addressed with due regard to sustain inclusive involvement. Respondents describe a range of procedural shortcomings to do with communication:

* Not being listened to
* Not being given equal power and respect
* Feeling inadequate because information at the heart of discussion items is not equally shared between staff/professionals and those disabled people participating as service user representatives
* Professionals not acting on service user suggestions or giving feedback
* An agenda had been set before the meeting so there is no opportunity to influence the process – a clear indication that service user involvement is not genuinely collaborative
* Service user agenda items are put at the end of the agenda and not discussed because of time constraints (meetings not chaired appropriately.

Participants reported feeling intimidated on occasions when we observe our commitment to encouraging a social model perspective gets shifted back to a medical model approach. When this happens the effect is that our efforts to focus on dismantling barriers are disparaged, usually by a reference to ‘individual parameters’ to what we are saying which has the automatic effect of diminishing our contribution and recycling negative assumptions about disabled people’s perspectives. Several service user representatives described exposure to these sorts of tensions or negative rhetoric about disabled people in meetings they attended and, as austerity policies took hold in the UK context of the past decade, they had noticed increased resistance to their perspective usually attributed to financial pressures on services.

The problems described above, particularly of not being listened to, leads to service users feeling that our knowledge is not valued as explained below:

*“It is diminishing to realise how service providers see service users. It is frustrating in the meetings to sense how little credence most of them actually give to service user viewpoints. If our view chimes with theirs they are positive and pleased with how things are going; if the service user perspective challenges their views then they tend to offer platitudes and try to swiftly move the discussion on.”*

One service user representative described their participation as a *‘waste of my time as they were not listening*’. Another stated that *‘the worst’* was when the professionals hosting the involvement activity did not value their experience. Another referred to the way health professionals talked about service users as if they were not actually in the meeting and it was common to hear of an assumption that service users will not understand the complexities of the decisions being made in professional meetings. Interestingly many respondents felt we learned a lot about how to assist our own advocacy from observing the way service providers talk about service users in meetings we are asked to attend.

We set ourselves the question of why, if we are not fully respected as service user experts, this might be so. Our findings suggest there needs to be a cultural change to practice on the ground and not just in policy aspirations, in a way that gives people choice and control over our lives, particularly in the health sector as the following comments encapsulate:

*“Many professionals mean well but can be tokenistic and patronising, especially in the health sector. It is a huge mind set for health to realise that disabled people want choice and control over their own lives although many disabled people who have not had the same experience as those who get involved in service-user representation simply accept this kind of treatment.”*

In the worst reports people felt that professionals were not listening to their views or dismissing them altogether:

*“They are working against me, not with me. They are making decisions on what they think is best for me but not really listening to me.”*

We are frustrated to have to point out that of course being a service user and a service user representative and a professional in one’s own right are not mutually exclusive; for all respondents our identity as a service user seems to dominate our encounters with professionals – even in the user representative experience of being deemed expert by experience. There are also more subtle points to make about disability amongst professionals – does it make a difference to participation of disabled service users when the professionals have lived experience of disability themselves, for example?

Most people who took part in the study thought they were treated differently if a professional was unaware of their service user role, and similarly, treated only as an expert in their own conditions if they were known to be a service user representative suggesting an a priori assumption of narrow expertise. Our experience of receiving services was typically reported as a ‘top-down’ experience, whereas people described their service user representation roles as a more equal relationship where we can challenge decisions and negotiate outcomes. This is attributed to the power imbalance being greater when we are receiving services. For some respondents, the chance to disrupt the usual service user-service provider power imbalance was part of our motivation for taking on and sticking with the representation role.

The following example illustrates why this might be so:

*“For example, I went to the customer service area, just as a service user, just for me, and the receptionist was very abrupt .. I just sat there in the waiting room feeling overwhelmed. When I was being a rep I would go straight to the desk and be welcomed.”*

For others, the power imbalance between themselves and service providers proves intractable:

*“In some services, regardless of whether I am a service user or a rep, I have been disregarded, patronised and infantilised. It hasn’t made any difference if I am rep or not.”*

Someone else described how difficult it was when they had been working side-by-side with professionals as a representative and then suffered a relapse. They felt there needed to be more thought about the relationships that develop through being a representative and how these are managed if you become unwell:

*“The hardest part was when I had a relapse everyone had seen me being well, speaking confidently and it is all the harder to fall when you are back at their door, needing their help.”*

Other comments acknowledged that relationships between service providers and service users ‘work both ways’ and some professionals feel their own capacity to interact limited or un-nerving, particularly if we have complex needs and are at the same time able to knowledgably represent ourselves and others.

Our results suggest a tension around the position of service user representatives in the eyes of service providers: as service users we seek their views as providers but in the role of a user representative the tables are turned and professionals must seek our views. In the context of service user representation a different mode of engagement between disabled people and providers transpires. If professionals habitually do not listen and act on the views of service users when we are advising on policy and services then our experience of being service user representatives is the same one we feel when denied choice and control over our lives. It must also be noted that taking control by challenging poor services can take a toll on service users:

*“Just thinking about the impact that can have on you, not just the experience of being humiliated but the experience of trying to explain why that has an impact on you and that being disregarded as well, then that can undermine your confidence and then it becomes more and more difficult then to access services in the future.”*

*“Negative experiences become part of your private experience and can be very harmful”*

Negative experiences of service user representation can push us back into that grey area of uncertainty about whether or not we have been taken seriously.

The headline finding of our research points to an imperative to ensure that the conditions of oppression are not reproduced for disabled people through our experience of service user-representation; this is of fundamental importance for the liberation struggles of all disabled service users.

And so we see from the results of our research that disabled people’s experience of service user representation in the UK is not commonly experienced as entirely satisfactory or meaningful. To facilitate our own more effective contribution to social and service change we therefore also asked questions about what would need to happen to facilitate better participation and participation outcomes. Taking the perspectives of disabled people seriously would lead to better experience of service user-representation for those who take on this role with considerable potential for greater impact on changing services. This is the focus of our discussion.

**Discussion**

Our findings are robust being built on extensive data drawn from a diverse sample of service user representatives, some who have many years of representative experience with a wide range of organisations, others newer to the role and in the early stages of working with services in a representative capacity. The depth and breadth of issues raised confirms that it is important to look carefully at the impact on service users of becoming service user representatives. Service user involvement should always be mutually beneficial and strategies need to be in place to make sure this is the case.

In terms of the themes of this Special Issue, the project conducted by Shaping Our Lives is significant as an example of a collaborative activist project because it illustrates the useful insights and outcomes that can emerge from a partnership between Disability Studies academics working as disabled activists alongside other disabled activists. Patricia Chambers’ sharing of her thoughts about her experiences as a service-user representative, which led to the development of this research idea, happened within a setting where disabled people, talking to each other, feel their perspectives and experiences will be listened to and acted upon.

We have sought to disseminate our research findings to service providers, for example through presenting at the European Conference for Social Work Research (2018). In addition we share our findings through Shaping Our Lives national networks of disabled people’s organisations, and we seek also, but not exclusively, to publish our work in academic journals. Reaching activist, professional and academic audiences is a key motivator for our research which seeks to pioneer connections between the three stakeholder worlds.

To extend the impact of our work one of our authors, Colin Cameron has been able to introduce the project report and its related guidance resources directly into teaching on an undergraduate module in the Disability Studies at Northumbria University, UK. In this way a new generation of potential service providers, academics and disability activists are being encouraged to reflect on what disabled people get out of service-user representative involvement rather than accepting at face value that the time and energy of disabled people can be appropriated solely to add value to the services they are involved with. The report and its resources have, furthermore, been used as a training resource with disabled people involved in social work education at the same university.

As inclusive research, involving experienced and novice disabled social researchers alike at all stages of the process, we are proud to claim our study as authentic disability research, grounded in the real concerns of disabled people working within and beyond service user, academic and professional stakeholder communities of practice. While it is impossible to evaluate whether the research will bring positive changes to the lives of disabled people in order to claim any ‘emancipatory’ credentials (Mercer, 2002; Cameron*,* 2014), we are pleased that the project was shaped and operationalised entirely by disabled people. The insights generated, as well as the report, the guides and action steps which we will go on to outline in conclusion, have highlighted development strategies that may not have emerged without the fusion of academic and activist perspectives that reside within our DPO Shaping Our Lives.

In 1992:102 Oliver wrote that:

*Disability research should not be seen as a set of technical objective procedures carried out by ‘experts’ but part of the struggle by disabled people to challenge the oppression they currently experience in their lives.*

In our study we have tried to operationalise the aspirations for disability research Oliver articulated almost three decades ago. Disabled people in service user representative organisations like Shaping Our Lives share a common aim and purpose of engaging in the struggle for a barrier free equal life. Some of us are involved in university research and teaching, others in self-advocacy groups, some in patient panels, others in access projects and so ons. As Campbell observed ‘the disability movement is like a jigsaw – each piece is vital for the true picture to emerge’ (Campbell and Oliver, 1996:199).

The point of being united as disabled people across academic and activist communities in a common struggle against oppression is that collectively we combine a unique set of skills, talents and experiences to be shared as resources for the advancement of our shared liberation struggles. Combining ‘academic’ and ‘activist’ perspectives and resources, as in the project described in this paper, serves the original values and intentions of *Disability & Society* to bridge the gap between the academy and activists, engage with struggles taking place locally, nationally and internationally and to improve the lives of disabled people according to the priorities of disabled people themselves.

**Conclusions and Recommendations**

As final outputs from the project we developed resources that will benefit those keen to take seriously what disabled people say about how our involvement as service users can be improved In addition to the main report we compiled a Guide for Service Providers and a Guide for Service Users. For each we extracted a comprehensive list of actions service user representatives say will improve involvement which can all be freely downloaded <https://www.shapingourlives.org.uk/resources/our-resources/all-publications/improving-understanding-of-service-user-involvement-and-identity>*.*

We have been able to show that when service user involvement is respectful and inclusive this has a positive and mutually beneficial impact for professionals and service users alike. However, it is also clear that when arrangements for service user involvement do not pay sufficient attention to the dismantling of barriers to participation, we experience organisational exclusion based on disabling attitudes; we are left experiencing our contribution to service development as neither adequately respected nor properly valued. Further, a problematic tension has also been uncovered whereby service user representatives notice we are sometimes treated more respectfully as a representative compared to when we are using services. This has caused us to question a double standard and query whether our knowledge gained through lived experience is really valued in either role.

Our data shows that disabled people can be effective service user representatives if training and support appropriate for the role is provided. To augment our access to, and benefit from service user representation, we conclude both participation and training should be accredited. We heard of isolated good practice examples of training to develop the knowledge and confidence to take part as a service user representative; however, this was something only three people mentioned in the research that deserves to be rolled out more widely. Accredited training for disabled people to build confidence for our role in service user representation would help to bring us in to more equal light both within, and beyond, our user representative roles.

**Action**

If activist-led academic informed research by disabled people can find a place in a world leading journal such as *Disability & Society* then we would like to seize the opportunity to bring our ideas for action to its international audience. We have identified steps professionals can use for immediately improving service user involvement built from the recommendations service user representatives have contributed to the research. These relate to Training, Access and ensuring Equal Participation. We propose small, doable consistent action steps and habits that will create more respectful and inclusive service user participation and are key to making sure that people who take on the role of service user representation have positive experiences and outcomes from being involved. Over time each step will improve involvement of service user representatives in ways that will make it more and more possible to drive through better, value for money, cost effective services that disabled people value.

Our four practical steps for improving involvement of service user representatives, applicable in any context are:

* Step 1 - Create profiles of the service users you work with and build better connections with them

* Step 2 - Set some 30-day goals for improving involvement of service user representatives
* Step 3 - Include a call for service user involvement in any communications you send to your service user community
* Step 4 - Follow up on disabled people’s experience of involvement; ask for feedback

Disabled service user representatives involved in our research say these strategies comprise the first practical steps in taking seriously of strengthening our involvement.

Clearly these practical steps belong to a professional agenda and there are deeper questions to work out about how to meaningfully and sustainably shift the balance of power in service user representation. The range of terminology used to refer to service user involvement, often termed ‘co-production’ for example which we have not explored in this paper, threatens to obscure experience led research, immersing disabled people in rhetorical jargon that suggests inclusive participation but which in reality enables service providers to construct the nature of participation and determine its personal cost to service users. Many questions need to be asked about the way in which service user involvement is operationalised. In the UK there are important new questions arising for example, about the changing nature of service user involvement in the context of a shift towards a consumer based model in services via a market model which Shaping Our Lives is concerned with.

To conclude, our paper serves three purposes. First, we have offered an account of disability research which unifies academic and activist agendas that can be used and to inform future enquiries and research practice by disabled people, service providers, and researchers, including students. Second, through the process of producing the research and writing about it, we are changing ourselves and our service representation activities beyond it; for example, through the various networks which Shaping Our Lives has it is proving possible to use our learning to drive change even at the level of our own conversations. And third, we hope the paper will inspire new energy and possible directions for understanding the politics of involvement at the level of listening to experience and also the level of changing ideas relating to participative democracy and disabled people’s activism. The aim of the paper has been to stimulate debate and dialogue around these topics in terms of how they may play out in disability service settings.

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