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Service User Involvement and COVID-19—An Afterthought?

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Abstract

We are researchers and activists working in the field of service user involvement for many years in the UK and internationally who are concerned that, during the COVID-19 pandemic, years of progress in service user involvement have been unravelled by service users being left on the outside of key decisions and matters affecting their lives. Instead, we argue, they have become an afterthought. As authors, we combine both academic and service user experience and have been involved in advancing practice, understanding and guidance about the significant contribution that service users bring to knowledge production. This article examines the issues by focusing on the journey of service user involvement before and during the pandemic, as well as on what should come after. Turning to the experiences of disabled people as a case study example, we argue that going back to 'normal' would be fundamentally flawed, as evidenced by the marginalised way in which service users have been treated during this period of societal crisis. Our article concludes by urging a reflexive stance to ensure service user involvement re-establishes its pivotal position in public policy and practice.

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Introduction

We are a group of five authors sharing between us a wide experience of service user involvement, from both lived experience standpoints and as academics researching and writing on this topic over several decades. Last year saw the publication by Routledge of our edited international handbook on service user involvement (McLaughlin *et al.*, 2020b). Following this, we have felt compelled to write this article, such is our concern about what we perceive as a waning of focus on the voice of the service user during this time of crisis. Against this backdrop, we question if the pandemic has highlighted the extent of structural discrimination and exclusion more so than it has reinforced a focus on individualised problems.

Service user involvement in public policy has been well established in the UK for over thirty years (Duffy and Beresford, 2020). As such, expectations around involvement are now legally mandated in key aspects of health and social care (e.g., Section 19, Health and Social Care (Reform) Act (Northern Ireland) 2009) and are embedded as core features of social work education (DOH, 2002; DHSSPS, 2003). Much has also been achieved in positively elevating the contribution of lived and experiential knowledge to important debates in social work education, in particular (see, e.g. Završek, 2009; Robinson and Webber, 2013; Levy *et al.*, 2018; Raikes and Balen, 2018; Videmšek, 2018). New texts (Beresford *et al.*, 2021; Williams *et al.*, 2021) exploring coproduction in the context of COVID-19, drawing on the experience of service users and carers in the UK and beyond, highlight their perception that the pandemic was seen by many policymakers as too urgent and too much of an emergency to allow for the ordinary operation of public and patient involvement. These texts also point out that many disabled service users, for example, would have had much to offer in terms of sharing understanding of the restriction of activity experienced by many more during lockdown. This insight could have been beneficial, but little effort was made to tap this experiential knowledge.

An official assumption has been made that service user involvement is too time consuming in the recent context of crisis and rapid decision making (Gilmore *et al.*, 2020). However, we argue that, with the availability of appropriate access and support, service users are as capable as anyone else of working under pressure and to deadlines. For many people in receipt of services, living with uncertainty and unpredictability is part of what they live with daily with 'restriction' existing long before COVID-19 (Clifford, 2020). The fundamental question core to this article is, then: why are service users being treated as an afterthought? Before this crisis, in university education and organisational contexts, particularly those that were service user led, we were endeavouring to

ensure that co-production and involvement were integral to daily practice. It had never been perfect, and was in need of constant review and improvement (*Shaping Our Lives, 2017*), but its importance was at least agreed upon. Throughout the pandemic, however, we have observed in online meetings and other exchanges, expressions of obstacle, barrier constructions and excuse, the like of which we had assumed were a thing of the past:

We need to clarify our own thinking before we can get the service user perspective.

Service users don't have the technology to facilitate their involvement.

The guidance says 'where possible' so that means we don't have to involve people.

The sentiments behind such responses underscore some worrying trends about power and inequality that will be explored in this article. Where access and support needs are met, service users are more than capable of being involved 'from the start' to meaningfully contribute to planning. Surely, it is also disrespectful to ask service users to contribute when a plan of action has already been crafted and decided upon without their involvement. We can cite a significant body of evidence-informed research contradicting this type of approach which is totally at odds with all meaningful theoretical models of good service user involvement (see, e.g. *Duffy, 2008; Duffy et al., 2017; Shaping Our Lives, 2017; Kearns and Carton, 2021; Bell et al., 2021; Loughran et al., 2021*). To bring service users to the 'virtual table' at a stage when thinking has already been developed not only subsidarises the status of their knowledge, but arguably is a form of epistemic discrimination where more power is afforded to expert knowledge and service users are treated as being less equal. We also recognise that access to the Internet may indeed be an obstacle to 'virtual involvement' but, from our experience, service user involvement can take place where there is willingness and commitment to go the extra mile to overcome such barriers (*McLaughlin et al., 2018*). In saying this, we also recognise there is an unspoken inequality amongst those living in such poverty that access to Wi-Fi or devices is unattainable, a point we return to.

At a time when service users are suffering through COVID-19, surely we all have a moral duty to ensure their voices are both front and centre, and not something thought of afterwards. Given what has been fought for on the journey of service user involvement, we feel there is much at stake.

Where have we come from?

The failure to engage with service users and carers during the pandemic has to be put in context. One of the great, often unheralded

achievements of public policy from the late twentieth century onwards has been its increasing commitment to involve the public, patients and service users at its heart (Beresford, 2016). This can be seen as one of the positive consequences of a growing turn away from centrist big state policy-making (Simmons *et al.*, 2009) leading to the benefits of the welfare state, which may have had positive intentions, but could sometimes be experienced as paternalistic, patronising and controlling. Thus, we have seen both requirements for and a new culture committed to citizen, patient and service user involvement in public policies and services. It has extended from participation in developing, evaluating and regulating public provision through to wider involvement in its professional education and learning and quality control (Levin, 2004; Duffy, 2006). One of the spheres in which such innovation has been most developed has been in the field of social care and health, with, for example, requirements and central financing for such user and carer involvement built into every aspect and stage of professional social work qualification in the UK (McLaughlin *et al.*, 2020b). It is also worth noting that the joint IFSW and IASSW Global Standards for Social Work in August 2020 stated that social work education programmes: ‘*must* (italics in original) ...develop a proactive strategy towards facilitating Service User involvement in all aspects of design, planning and delivery of study programmes’ (IFSW and IFSW, 2020).

This participatory and democratising thrust to policy development has not always sat comfortably with the shift to market-led and neoliberal politics, but the latter’s rhetoric of ‘consumer choice, voice and involvement’ has helped provide an impetus to match the pressure for involvement coming from grassroots new social movements, including those of welfare service users which began to emerge in the 1980s (Todd and Taylor, 2004). However, there are now concerns, expressed particularly by service users, carers and their organisations, that the large-scale emergency conditions engendered by the COVID-19 pandemic may be imposing an unhelpful watershed in this widely welcomed development (Gilmore *et al.*, 2020; Pring, 2021). We have seen it in the processes for developing policy, research and analysis. The mantra has tended to be, this crisis is too urgent; there just is not time to listen to people in the firing line however much we recognised the value of doing so in normal times.

We may argue that the results have in many ways already been catastrophic. If we had gained the most experience involving and listening to people who are long-term users of health and care services, it was their experiential knowledge that was now most needed to be sought and listened to. Sadly, it generally was not. Thus, while large numbers of people stood on their doorsteps clapping the National Health Service (NHS), older and disabled people were being discharged precipitately to residential and domiciliary social care services already in crisis; creating

death zones, rather than safe havens, where disproportionate numbers of both service users and workers have died (Samuel, 2020a; Scobie, 2021).

It was only after pressure from disabled people's organisations that data on the death rate for disabled people from COVID-19 was collected (Matthews, 2020a, b). The adjusted results indicate that disabled men were nearly twice as likely to die as non-disabled men and disabled women two and a half times more likely to die than non-disabled women. The report by the Office for National Statistics suggests that these figures, if anything, are likely to be an understatement (Pring, 2021). Yet, little if any effort was made to involve these groups in developing policy, practice or research priorities although the experience of many living a life routinely 'locked-down' could have offered very helpful insights into developing evidence-based policy and practice to combat resulting mental distress and other damaging effects (Pring, 2021). Does the exclusion of service users and carers in this time of crisis thus highlight fundamental flaws in terms of what we had taken for granted as 'normal' in regard to service user involvement? The next section addresses the issues, as we see them, in more depth.

We cannot go back to normal

The apparent subjugation of service user experiential knowledge, and relegated importance in this pandemic, justify the critical questioning of prior assumptions that the UK, in particular, was in an established place with regard to non-tokenistic and meaningful service user involvement. This is in spite of what many social workers, especially, would have hitherto assumed was the case (Dreissens et al., 2016). It is, therefore, worth examining this chasm between expectation and reality through the lens of power relations focusing specifically on disabled people's experiences.

Disabled people have been disproportionately negatively impacted by the COVID-19 crisis and lockdown. The Health Foundation has identified that six out of ten people who have died from COVID-19 are disabled, and a range of other negative issues have been identified, including, for example, reduced access to health services and support at home; loss of confidence and independent living skills; isolation and loneliness; and lack of access to basic life necessities such as food (Meakin, 2020; Health Foundation, 2021). This crisis comes after a decade of 'welfare reform' under successive Conservative-led and Conservative Governments, continuous slashing of public services and what has been described by Clifford (2020) as a 'War on Disabled People'. Toynbee (2021) reported that in March 2021, the National Audit Office warned that 94 per cent of councils would have to cut spending, and that social care is the biggest slice of their stricken

budgets. Disabled people, carers and older people will thus be disproportionately affected.

Whilst we do not wish to exclude other individuals where the impact of the pandemic has increased many people's vulnerability and isolation, by placing the primary focus on disabled people we aim to identify key messages that can inform a wide range of contexts. There have been considerable efforts made over recent years to include those least visible from the most marginalised communities to have their voices heard and experiential knowledge valued. For example, carers whose roles have been exacerbated during lockdown having had no breaks and less support (Carers UK, 2021); people with mental health difficulties who have been significantly compounded by reduced support and increased stress and anxiety (Mental Health Foundation 2020); and the refugee and asylum seeker communities, already the most vulnerable in society, who have faced increased challenges intensifying the hardships they ordinarily felt (Finlay and Hopkins 2021). As we later identify, increased efforts are required to promote well-being as well as to regain trust and confidence in people whose voices are crucial to informing education policy and practice.

Going back to the way things were done before the pandemic in terms of service user involvement would be misguided unless there is a considered and reflective focus on why power relationships have shifted during the Covid crisis. It is, therefore, worth considering the findings from *Shaping Our Lives* (2017), the national network of service users' organisations, which signalled concerns around service user involvement in the years before the pandemic. Of particular note was that many disabled people's experiences as user representatives had left them feeling dissatisfied and let down. Feelings of tokenism and lip service from professionals were described in the following terms:

- frustrating as it takes so long to make a difference;
- annoying as it became clear that it was a tick box exercise;
- patronised as they were not listening to what I had to say; and
- if it is someone not committed, it is depressing, frustrating and head-bangingly annoying

(*Shaping Our Lives*, 2017, p. 14).

One of the key issues underlying these statements is disabled people's ever-present alertness to power inequalities, and with what Du Bois (2003, p. 5) described, in the context of racism, as 'double consciousness'—the knowledge and sensitive awareness that one is always looked upon as 'a problem'. In relation to disability, this is arguably to do with an understanding that, however, nicely professionals smile, you are always regarded as someone who has something 'wrong' with you. In many ways, this is unsurprising, for this could indicate an institutionalised way of thinking about disability. The Equality Act 2010, for

example, which establishes the UK context for social work practice, states that ‘You’re disabled if you have a physical or mental impairment that has a “substantial” and “long-term” negative effect on your ability to do normal daily activities’ (GOV. UK 2021). That is to say, it establishes an individual or medical model definition of disability, identifying disability as the outcome of impairment and classifying it in terms of deficit (Cameron, 2014).

This model is reflected in many social workers’ and others’ insistence on using the term ‘people with disabilities’. As Michalko (2002) has observed, ‘person-first’ ideology involves the downplaying of impairment, which is regarded as distinct from primary experience as a person. It is thus considered as a disavowal of both impairment and deviance, but reinforces a view, which accepts as uncontroversial and natural common-sense the assumption that impairment is something that can only be experienced as a burden or an inconvenience. It thus involves making an assumption that it is a kindness to overlook impairment while relating to the (presumably normal) person trapped within the flawed body. Most importantly, it fixes disability as an individual trouble rather than as a social issue (Wright Mills, 2000), legitimising professional intervention and the provision of ‘care’ (rather than access) as an appropriate and adequate social response. It is over three decades since Richard Wood, then Chair of the British Council of Organisations of Disabled People, stated that disabled people seek independent living and control over their lives rather than care: ‘The concept of care seems to many disabled people a tool through which others are able to dominate and manage our lives’ (Wood, 1989, p. 199). Yet, this seems a view that is often still neither listened to nor understood, whilst the idea of care conceivably remains unexamined and unproblematised.

Through incessant use of person-first terminology, social workers—even if unconsciously and unintentionally—entrench individual and personal tragedy model disability discourse. As Simpson *et al.* (2019, p. 7) note:

Language is used to create and shape institutions and... institutions in turn have the capacity to create, shape and impose discourses. Institutions have considerable control over the organising of our routine experiences of the world and the way we classify that world. They therefore have the power to foster particular kinds of identities to suit their own purposes because they are primary sites for ‘reality construction’.

Social work is one such institution and, as professionals, social workers are invested with power. As agents of the legal system, their words are regarded as having authority. They have what Tew describes as ‘power over’ (2006). Their use of person-first language plays an important part in obscuring understanding of disability as a socially created category. It has the further effect of blocking development of political consciousness

among disabled people who, internalising the values of the society which oppresses them, often then unquestioningly accept the way they are represented (Cameron, 2007; Cameron *et al.*, 2020; Clifford, 2020).

There needs to be a shift among social workers from thinking about disability as an individual trouble or attribute to recognising it as a social issue and as a form of structural oppression (Cameron, 2014). This is a position that has been taken by the Disabled People's Movement for decades now, since the Union of the Physically Impaired against Segregation stated in 1976:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS, 1976, p. 14).

For user involvement to be meaningful and purposeful, it must be respectful. There is a large body of Disability Studies literature by disabled writers and academics outlining the altered subjectivity of people with impairments who have 'claimed disability' (Linton, 1998) and asserted their rights to be as they are, different but equal, in the face of oppression. Impairment is not a tragedy; it is a fact of life. What is tragic is the way society responds to impairment. There has been much talk about listening to disabled people, but perhaps not enough reflection. Rather than going 'back to normal'—returning to things just as they were before the Pandemic—change is required and a re-focused, reflexive debate about the true state of service user involvement. The following section focuses on the challenges and threats as we currently see them.

The threats as we see them now

The public face of the COVID-19 pandemic had been managed between March 2020 and March 2021 by daily ministerial briefings with two experts, one on either side of the minister, to provide an 'expert opinion' if this was required. The presence of the two experts was to assure the general population that decisions on lockdown for example, hand washing, the use of masks or the two-metre social distancing rule, were all based on scientific evidence. However, this has also represented a (re)-turn to expert knowledge, or to be more accurate, scientific knowledge. Michael Gove, a leader of the campaign to leave Europe, claimed on 3 June 2016, 'people in this country have had enough of experts' (Clarke and Newman, 2017, p. 111). However, as Lavazza and Farina (2020) have shown, government responses to managing COVID-19 have seen some official acceptance of medical expert knowledge (virologists, epidemiologists, public health and statisticians) often used to justify unpopular measures like restricting people's liberty or closing down sectors of

the economy. Such expert knowledge has been essential in developing vaccines and new ways of caring for those with COVID-19 even if the Scientific Advisory Group for Emergencies could not always agree. It is also worth noting that science is not able to answer the moral questions of responding to a pandemic as science is non-normative, resulting in the need to make choices, for example, should the UK have continued with its initial policy of herd immunity to support the economy or moved quickly to a stringent lockdown to protect the health and welfare of citizens?

The two expert figures flanking a government minister helped to suggest a view of decisions being based, not on some political ideology, but on ‘objective’ facts. Such a position increases the credibility of the message and, in so doing, reduces critique, dissent or discussion. This was the case even though we were reminded on a number of occasions that as we had not faced COVID-19 previously, the Government was having to make decisions without the full knowledge of its impact. For example, during the first wave of the pandemic ‘Thousands of hospital patients were allowed to return to their care homes without a COVID test despite a direct plea to the government from major care providers not to allow the practice’ (Savage and Tapper, 2021). This exodus was engineered to free up hospital beds for COVID-19 patients and resulted in home owners being pressured into taking 25,000 residents back between 17 March and 15 April 2020 even though the majority of these had not been tested for COVID. Public Health England (2021) claimed that only 1.6 percent of care home deaths had come from discharged hospital inpatients. This finding is, however, challenged by Vic Rayner, Chief Executive of the National Care Forum, saying the government only considered those who had tested positive, ignoring that the vast majority were rushed out of hospital without any testing at all (Savage and Tapper 2021). Hopson (2020), the Chief Executive of NHS Providers, claims that sufficient testing of discharged patients to care homes did not start until 15 April when NHS trusts were asked to systematically test every care home discharge. Before that date, asymptomatic patients who were not tested were discharged to care homes. Hopson (2020) also notes that: ‘The scandal here is the repeated failure of politicians to solve our long-running social care crisis. And any public inquiry will need to look at the role that the lack of testing capacity and PPE has played in the high number of care home deaths.’

As the Nuffield Trust noted, this situation, despite warnings, led to an ‘extraordinary number of excess deaths’ (Scobie, 2021) amongst residents, not to mention the impact and increased death rate of care staff. An unspoken message throughout this period was also that ‘we were all in it together’ and that we should all be happy with our lot and act as responsible citizens. We now know that some of us were more in it together than others, particularly those who were older, disabled, male,

living in a more 'deprived' community and were members of a Black, Asian or Minority Ethnic group (PHE, 2020). Decisions about those who have been isolating have been undertaken on the basis of reducing their risk of catching the virus, with debatably little regard to their mental health or wellbeing more generally. It is also becoming clearer that many people, not just those who had a serious infection requiring hospitalisation, will have ongoing needs, both medical and non-medical, going forward. The *BBC News* website has also reported that experts are concerned that our focus on COVID-19 could lead to between 7,000 and 35,000 extra cancer deaths <https://www.bbc.co.uk/news/health-53300784>.

In all of this, lived experiential knowledge has been marginalised (McFadden *et al.*, 2020). The views of those on the receiving end of services have been silenced (McLaughlin *et al.*, 2020a). As such, we are in danger of making decisions and judgements based on partial knowledge. Not involving those on the receiving end risks poorer decision-making and unintended consequences. McLaughlin *et al.* (2020a), reflecting on the contributions from social work educators from twenty countries on how they responded to COVID-19, noted that there was a deafening silence on the place of service users, concluding that service user involvement was no longer essential but merely desirable in more challenging times.

Whilst it is understandable for services to claim, as stated earlier, that they need 'to clarify their position first', it does not mean that this is the right approach. Such a view is at best patronising and at worst failing to grasp the expertise based on experiential knowledge to develop more effective responses and to address the questions and priorities of those in receipt of the services (McLaughlin, 2010). Then the counter argument may be, 'Yes, but we have to move quickly, and service user involvement is too time consuming'. Whilst there can be a degree of truth in this view, with access and support requirements met, service users are as capable as policy makers or professionals of working under pressure and keeping to external deadlines. It is also true that time spent ensuring all key stakeholders are involved in problem solving is likelier to lead to better decisions which are owned by all stakeholders and, in the longer term, lead to a more impactful expenditure of limited resources. Lastly, we have anecdotally heard from those, who we would normally view as pro-service user involvement, explaining that they had not involved service users as the service users did not have access to or could not use the technology to participate. This is certainly true for some service users, but not for all. COVID-19 has highlighted a fault line between those with digital access and those without. To involve others, we may need to go back to advocating greater access to virtual and online platforms for service users to ensure meaningful involvement or risk further marginalising groups within our society. The advances made in the greater connectedness achieved through virtual and online environments

have undoubtedly created greater opportunities for some service users and, at the same time, reduced opportunities for others. It should not be beyond the creativity of organisations or universities to find ways to overcome such technological hurdles—if they want to. The next part of our article focuses on what needs to be considered as part of the forward journey.

Key messages that need to be heard

As we look towards a ‘new normal’, it is important to reflect on key learning that can shape new structures for involvement. As has been highlighted, people who ordinarily experience disadvantage and discrimination were not on a level playing field with professionals and policy makers when the pandemic response strategy was implemented. It became apparent very quickly that those who often found themselves at the margins of service provision were being pushed even further away. Research undertaken by Turning Point, for example, revealed that an ‘unprecedented’ number of ‘Do Not Resuscitate’ forms had been received from doctors that it believed were illegal (Thomas, 2020). A statement from the chief executive, Julie Bass, demonstrates a worrying level of institutional discrimination and persecution against people with learning difficulties that should have long since been eradicated:

Making an advance decision not to administer CPR if a person’s heart stops, solely because they have a learning disability, is not only illegal, it is an outrage.... We are seeing DNR orders that have not been discussed with the person themselves, the staff who support and care for them, or their families. This is very concerning as it may potentially lead to people being denied life-saving treatment that other patients would be granted (<https://www.hsj.co.uk/coronavirus/unprecedented-number-of-dnr-orders-for-learning-disabilities-patients/7027480.article>).

Despite the increased chances of people with learning difficulties dying from COVID-19, it took a campaign led by families, supporters and people impacted upon by this decision, to change the government’s plans and prioritise a vaccination programme (Sample, 2021). The introduction of the Care Act Easements under the Coronavirus Act 2020, enabled councils to suspend duties to carry out needs or financial assessments, develop or review care and support plans and in extreme circumstances meet needs other than where this would be a breach of human rights. Eight authorities are known to have taken up the easements fully, with one limiting its duties to meet unmet eligible needs and reduce care packages for residents. One other authority dropped its plans to limit its duties when faced with a legal challenge from a disabled adult (Samuel, 2020b). Whilst it is encouraging that the majority of authorities did not

take up easements, the small number that did risked increasing pressure on disabled people as a statement from Liberty's policy and campaigns manager summed up:

We were concerned by these easements when the coronavirus legislation was introduced because time and again, those at the margins feel the sharpest end of a crisis. What we weren't anticipating was the eagerness of some councils to trigger them without full assessment and consultation... The Government and local councils should be working to shore up – not weaken - support for disabled people, their carers and those who rely on social care during this pandemic. We need to come through this crisis the right way – with all of our rights intact (Grant, 2020).

Much reparation is, therefore, needed in order to redress the balance of negative values that have been conveyed by these actions. The social work profession embodies values to ensure that people are treated with dignity and respect and which promote social justice. Such values are reflected by the commitment the profession has, as a formal requirement of education, to ensure that people at the receiving end of services are included at all levels of social work training (DOH, 2002).

The IFSW and IAASW Global Standards for Social Work Education and Training (2020), mentioned earlier, underscore a commitment to service user involvement in social work education internationally. Recent research, however, undertaken with twenty countries since the start of the pandemic demonstrates that this has not been achieved (McLaughlin *et al.*, 2020a). The focus on adapting to online learning and sustaining student engagement would suggest that service user involvement became a lower priority. Whilst maintaining student engagement is clearly a priority and everyone was adapting to difficult circumstances under pressure, not having the same commitment to service user involvement is a worrying message. If involvement had been truly owned by those who have been contributing and arguing for this for years (McLaughlin *et al.*, 2020b), this reaction would not have happened as the quote from the aforementioned research asserts:

Such a position neglects the daily experience of service users and reinforces the view of service user involvement as a luxury or tokenism that in times of true difficulty becomes expendable (McLaughlin *et al.*, 2020a, p. 979).

The barriers that people have encountered are, however, not new barriers, they are arguably more an illumination of the creaking structures that have been propping involvement up in this way for too long, underscored by the previously mentioned research by *Shaping Our Lives* (2017). Nonetheless, considerable progress has been made in recent years to engage with people feeling most stigmatised and excluded from having a voice in professional training contexts. For example, the 'gap-

mending' approach originating from Lund University, Sweden, introduced in the UK in 2015, has brought students and social workers together in communities with people who did not have the confidence to enter a university (Casey, 2018). Through co-produced learning, 'Mend the Gap' projects, founded on experiential knowledge, have transformed outcomes for those participating. For example, asylum seeker parents have described how their perceptions of social workers have changed and unaccompanied asylum-seeking young people have co-produced a ten-step guide for social workers meeting migrants on arrival (Casey et al., 2020). As noted earlier, these communities have been hardest hit during the pandemic particularly, due to living in poverty, adversely impacting their access to Wi-Fi. This has meant that despite the commitment people still have to contribute to social work education, they have been excluded by not having the means to participate. Extra efforts are thus required as we look towards the 'new normal' to ensure that progress is sustained, and to redress the way people have been de-valued during these pandemic times. This is a responsibility and an opportunity for us all to put things right. Next we turn to the future!

Conclusions: looking to the future

Listening in shock to the *BBC News* story on 18 March 2021 strengthened our determination as authors to express our concerns about the apparent demise of service user involvement, when we would argue it is needed most. Already referred to in this article, this news item reported the findings of the Care Quality Commission in England about the possible breach of individuals' human rights in over 500 cases of 'Do Not Resuscitate' (DNR) orders during the pandemic:

Some 508 'do not attempt resuscitation' (DNAR) decisions made since March 2020 were not agreed in discussion with the person or their family (www.bbc.co.uk/news/health-56435428, accessed 27 March, 2021).

Also reported in the BBC piece is the reference to 'unprecedented pressure' and 'rapidly developing guidance' in the background context to how clinicians were making such critical decisions. The consequences of actions such as these are, however, inextricably linked, we argue, to the most basic and absolute Right in the [European Convention of Human Rights](#), that concerning the 'Right to Life' (Article 2, ECHR). Working under pressure and having to think quickly in terms of procedures and guidelines are no excuses for not thinking about service user involvement from the outset. An example such as this, and others we report in this article, could potentially do untold damage; unravelling years of good practice in health and social care person-centred and co-produced practice.

We do, nonetheless, believe that service user involvement will re-establish its place and focus, but we also recognise that this process will necessitate a re-examining of the problems referred to by *Shaping Our Lives* (2017). However, this will require pro-active steps from those in positions of power, along with honest and open debate which recognises that mistakes have been made. In re-calibrating, this will call for a reflexive debate with service users at its heart, not being ‘consulted’, but being directive in re-stating that lived, experiential knowledge can fit the contours of all decision making, irrespective if this is crisis and pressure driven. As said before in this article, this is the way many service users have had to live their lives, in oppressive contexts where marginalisation typifies everyday life. As we move, hopefully, towards seeing an end to this pandemic, we want our article to encourage readers to reflect on why service users have been side-lined in terms of not having their voices heard. The implications of this inform three key recommendations:

1. Social work regulators and universities need to prioritise the involvement of people with lived experiences within academic structures. We suggest that service user led organisations are best placed to take a lead on involvement activities. The initial aims of meaningfully integrating involvement at all levels of education have never fully been achieved across the sector. Now is the opportunity to take a new approach and revitalise teaching and learning that is founded on experiential knowledge.
2. In the contexts of research, policy, practice and education, we urge social workers to reflect on the impact of the medical model, wherein disability is equated with impairment, understood as something which can only be experienced negatively and measured in terms of limitation and abnormality. Disability is not something people ‘have’, it is an oppressive social relationship. Living with impairment can, instead, give rise to insights and understanding that add value and interest to life. Difference, therefore, needs to be affirmed and included rather than treated as a challenge and as a problem to be solved.
3. COVID-19 has highlighted ways in which creative and imaginative use of technology can open up opportunities for bringing service users and carers to the heart of research, education, policy and practice. The latter domains are those which have previously typified opportunities for service user engagement. The adversity to which we have become acculturated, can therefore yield hope going forward, that if the will is there, meaningful involvement can again occur in the important areas identified.

In closing, we call for a re-focused examination of what service user involvement actually means. We do not believe this is about improving

training; it is more fundamental than this. It is about society seriously reflecting on the value and central importance of people with lived experience of receiving services. Service users have delivered in the past and will deliver in the future but the experiences of their marginalisation in this pandemic, when their voices could and should have been most loudly heard, will have to be openly reflected on to learn the lessons from this. We hope our article can be a catalyst for this debate going forward.

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