Including Our Self In Struggle: Challenging the neo-liberal psycho-system's subversion of us, our ideas and action

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Abstract: This article takes as its starting point the author's personal perspective and long term personal experience as survivor and activist/researcher to explore the ways in which the alliance of neo-liberal ideology and the psychiatric system has resisted the impact of mental health service users'/survivors' activism and instead sought to co-opt and subvert its language, ideas and initiatives. Drawing on the author's perspective, it looks first at how this has happened in relation to the language of mental health, exploring specific terminology. Then it examines how this has happened in relation to key ideas associated with survivors' collective action, including self-management, peer support and recovery. It show how 'our' ideas have been reconstituted to serve neo-liberal ideological goals. Thirdly it looks at how survivors' innovations have been obstructed and taken over instead by the dominant bio-medical paradigm. Finally it traces the way in which survivor knowledge has similarly been obstructed and appropriated. The article ends with discussion of 'two beacons of hope'; the emergence of Mad Studies and 'Gap-mending' which offer the possibility of challenging neo-liberal dominance and emphasises the need to support and safeguard these developing opportunities.

Key words: First person perspective, Neo-liberalism, survivor knowledge and activism, neo-liberal co-option, Mad Studies, gap-mending

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Introduction: Connecting self and psychiatric system

As mental health service users we are all to some extent subject to the dominant medicalised interpretations imposed on us. I include myself (as a cis male minority ethnic service user aged 72) in this no less than anyone else. It is how we are taught to understand ourselves, often the only model we encounter. In more recent years such psychiatric analysis has also been overlaid with powerful, dominant neo-liberal ideology and narratives with which it colludes.

It is central to our individual and collective struggle to be able to contest such understandings. For me, like many who begin to escape them, this has happened through contact, discussion and collective action with others with shared experience. Ironically though, while this may be the best, indeed only path to new beginnings and liberation, getting involved to bring about change – both within ourselves and in society more broadly, creates its own ambiguities and brings its own costs.

Not least this is because we have to engage with the structures of psychiatry and the broader politics that support and perpetuate them. We may start with our own developing understandings and collectivities, forged with each other, in our own organisations and movements. But if we want to achieve anything, we soon have to enter the lion's den. We have to take issue with the system itself. And that mainly means entering alien spaces and antagonistic

contexts. It may be that 'no person is an island'. Certainly no individual or group seeking change can be totally separatist. All we are then likely to be are hermits. So we have to become involved with the structures and systems of the world we want to change; its forums, its media, its 'science', its academia, its common-sense.

I believe that the black lesbian feminist Audre Lorde was right when she wrote, in the context of the white feminist movement, that, 'The Master's Tools Will Never Dismantle the Master's House' (Lorde, 2015). By this she meant that if we do things the same old ways, we will get the same old results. Thus it is so important that we work together in different, more equal, inclusive, humanistic ways, especially in our own organisations. But we will always be under pressure from ruling organisations when we engage with them, to do things in the same old ways – because that is how they work. We may start with the aim of changing them, but we know that they can insidiously change us.

This tension has special significance for mental health service users' struggles because at the heart of these is a search for a different way of conceiving of our emotions, experience, difficulties – *ourselves*; our 'treatment' and analysis. If
mental health service users' action is about anything, it is about including all of ourselves centre stage and being true to our experience and the knowledge that comes from it. Not only is the psychiatric system resistant to this, but as the agent of neo-liberal ideology, I believe it has (unintentionally or otherwise) increasingly worked to reinterpret, subvert and constrain us, our ideas, proposals and innovations.

I have charted these developments elsewhere as a service user. writer, researcher, educator and activist. I have done this in our own service user forums and media, as well as in mainstream academic, professional, policy and mass media (for example, Beresford, 2016). All

these latter impose their own constraints, although there are perhaps some signs of these being

loosened. But while I have sought to introduce my own and other people's lived experience and

experiential knowledge, I have not so far focused primarily on my own experience, views and

my own life and their intersections with these issues. That is what I want to try and do in this text

– because I think our strength is ourselves and the crucial problem of the psychiatric system is its

tendency to depersonalise and reframe us. Each of us needs actively to seek to challenge this, in

our own minds and in our broader discussions. So in this discussion my starting point is myself,

although I hope that this encourages others to reflect in the same way, feel more confident to

foreground their own experience in their struggles with the psychiatric system – as both service

user and activist - and question the non-personal nature of much psychiatric discourse.

The subversion of language and ideas

The issue of the psychiatric co-option of language and ideas was brought home to me

powerfully on one occasion when I had been speaking about mental health issues as an out

service user at a big event. When I finished a woman came over to me and asked enthusiastically

how long I had 'been cured'. She was a sister service user and I must have smiled at her in my

surprise. I remember saying, 'Well I wouldn't say I am cured, I think I've just got better at

understanding and coping with myself' and we had a conversation about it.

I don't know if she ever thought about that conversation again, but I certainly did. It

made me realise that I had no such concept, medicalised or otherwise, in my head, that my

experience, my distress, was something finite, time limited or 'soluble'. I did not think of myself

in terms of 'recovery', or any of the other terms that have been adopted and increasingly

subverted under modern neo-liberal politics in alliance with the psychiatric system. Instead,

reflecting on it now, I think I've just thought in terms of keeping going and hoping that the supports I have continue and that whatever the world throws at me, I'll have developed the resources to cope with it.

The impoverishment of language

There is no consensus about language or ideas in 'mental health' discussions; indeed discussion is inhibited by problems of language. Terminology has become a battleground. Here I want to explore this through my own personal experience and understanding and that of people I have worked and identify with.

These are issues which I have struggled to make sense of as an academic and researcher, but which also, of course I like everyone else contend with constantly as a mental health service user. Here is one of the meeting points between us as human beings with lived experience and the issues which we focus on that were formerly the preserve of traditionally understood 'experts' and 'expertise'.

I have come to realise that my use of language and ideas is necessarily idiosyncratic, but we don't often have chances to explore our personal use of language and concepts and the wider relations they might have. More often they are subjected to more formal intellectual, academic, professional and policy-related examination. Let me begin with language. My activism has included involvement in both the disabled people's and psychiatric system survivor movements; in both disability and mad studies, locally, nationally and sometimes internationally, which raises other issues for language use.

I have learned through all my activities in relation to mental health service user/survivordom a number of basic tenets about language.

There is no consensus about language – as I have already said. it is very rare if it happens at all that we agree terms. What I have learned is that if we want to maintain lines of communication, to try and use terms that are the least offensive to the most people and to apologise in advance for the misunderstandings and difficulties that terminology can leave us with. Even as I write here, I realise that some of the language I will use may create barriers and be misunderstood by some readers. We truly are prisoners of language in this field.

The meanings attached to words can vary enormously; this is at least partly because language here is the site of an ideological battle. So we may think we are on common ground because we use the same words, but we actually mean very different things when we use them. For one person the term 'service user' is liberatory, freeing them from the passivity they associate with 'patient'. For another, 'user' itself suggests passivity and has associations with drug use.

Language and terms use vary according to socio-economic and political system, ethnicity and culture; I have learned this collaborating with service users with different backgrounds and from different countries. The same terms can have different connotations for different people, in different countries. Not only the use, but also the resonance and echo of words and terms can be different for different countries and communities (Gorman, 2013). We have to get to know each other to learn what we each mean and to avoid misunderstanding or offending each other.

I have also learned something else about language in relation to 'mental health, perhaps the most important thing.
Arguing about it can be a very effective way of ensuring we do not even get to the starting point to do anything at all about the issues that concern us. As an early out-survivor academic David Brandon said of such non-service user commentators, always ready to put us right about our use

of language, 'They talk the talk, but they don't walk the walk'. So to try and be as inoffensive as possible, I tend to talk about 'service users/survivors'. Interchangeably – I use both to try and be as inclusive as possible.

Surviving?

Essentially I start as others a prisoner of the inadequate language of our field of human experience. I do want though to talk about some of the terms I do use, because even they raise further complexities – for me at least. One of my favourites is 'survivor'. I identify as a survivor. Indeed I identify as a psychiatric system survivor. This was a language I learned when I was involved in a pioneering UK mental health service users/survivors organisation, now sadly long defunct, Survivors Speak Out. Survivors Speak Out was a wonderful 'user led organisation', to start a career in mental health service user/survivor collective action. Among its activists were many of the true pioneers of such UK action, including Peter Campbell, Louise Pembroke, Mike Lawson, Chris Harrison, Viv Lindow and Jan Wallcraft. Survivors Speak Out pioneered action for change in thinking, activism, services and support. We drew a distinction between surviving distress and surviving the psychiatric system recognising the negative relations there could often be between the two.

Yet having said all this, having made clear that I identify with the term 'survivor', I have to be honest and admit that I have never really assumed I would 'survive'. Surviving for me and perhaps others has been a statement of principle and determination, of rejection and opposition. I hope to keep going, I am fortunate that I have supports, but I do not expect that I won't encounter situations or experiences I can't deal with. Surviving does not necessarily carry with it the assumption or expectation we will survive or some obligation that we must. I say this not least because many people I have known who have identified with that term have *not* survived.

Some have killed themselves, others have died much too early. I am thinking at the moment of

one particular greatly valued black activist colleague and friend who took her own life two years

ago Patricia Chambers yet who did so much while she was able to be here

(https://www.nsun.org.uk/news/remembering-patricia-chambers). My feeling is that their leave-

taking makes them no less survivors, because the light that burnt bright for me was their

continuing commitment to their beliefs and ways of seeing, rather than those of the psychiatric

system that too often had oppressed them. With support from each other, we do the best we can,

that is how I see it.

Language, ideas and the reductionism of the neo-liberal service system

For me, it is when I think of my own use of language and ideas in relation to my feelings

and distress and relate it to the service system that its reductionism becomes most evident. I am

only speaking for myself here. Perhaps our personal use of language about distress though is

something like our use of language about those we love. We have our own private thesaurus. We

use words in particular ways. We have pet names and there are secret meanings we share.

Certainly this applies to me. When I say to myself or those close to me that I'm 'feeling better' I

don't mean that I have decided that I am clinically improving. I mean I feel more ok. If I say I'm

feeling bad or feeling ill – and I know I say these things – then things are not so good, maybe

they make me feel frightened or miserable and maybe I am experiencing physical sensations too

– perhaps feeling all wired-up, or sick or just different. My body and mind have never existed in

separate compartments for me. I don't mean that I have internalised the aetiology of a 'mental

illness' or a particular diagnostic category. I'm just not feeling good! What may be no more than

a metaphor, perhaps borrowing from our greater familiarity and comfort with being physically

unwell, is made narrowly literal applied to perceived departures from a state of mental well-being.

However, the psychiatric system has not only reduced our complex moods, feelings, emotions and states of mind, with all their social, cultural and political relations to an ever–extending range of mechanistic individualising 'diagnostic categories'. It has also restructured numerous key ideas relating to mental health service users/survivors, in its own neo-liberal image. I want to refer to three such concepts because all three have gained increasing visibility and importance in mental health policy and practice internationally and all three have important ramifications for me personally. These are:

- Self-management

- Peer support

- Recovery

Self-management

I was fortunate. I had years of support from an experienced and open-minded psychologist under the UK National Health Service. She listened to me and connected her expertise to my difficulties and situation. In turn I listened to and learned from her. I reflected on what she said, worked out with her what could help, in terms of improving my understanding, of steps to take and goals to pursue. I tried to adopt and monitor actions and lines of thought that seemed to help and have done this since. I have tried to understand myself, others and my relations with them better. However, self-management in mental health discourse and policy has come to mean something very different. It is not about 'managing' in the sense of being able to

regain personal control, but 'managing' in the 'new managerialist' sense that has come to permeate modern neo-liberal social policy, including health policy. These are two very different conceptualisations; the first committed to the 'service user' being an active agent in their own well-being, the second shaped by the free market dystopian vision underpinning neo-liberalism.

Peer support

A term like peer support isn't one that comes naturally to my lips, or indeed I suspect to those of many other service users/survivors. It has the feel instead of professionalised jargon, like many terms that are meant to put people on the receiving end of policies and services centre stage, for example, 'self-advocacy' and 'personalisation'. But I can kind-of feel where it's coming from – us looking after each other and helping each other out as service users. And that has real resonance for me. I first felt it when I was in hospital and what I learned from other service users and the support they gave me, gave me strength, encouragement and more confidence. People saying to me when I was first admitted, 'if we can do it, so can you', gave me enormous reassurance. It became one of my mantras that kept me going and later, in turn, I would say it to others – true mutual support and reciprocity. I felt it even more when I first got involved in a survivor-led organisation, Survivors Speak Out, where for the first time I could have that liberating feeling that there was nothing *wrong* with me; that I could be myself, that I could be truthful with other people, that they would understand and there was the possibility of openness and equality. And we did things together in comfortable, helpful ways, committed to shared goals and values. And additionally service users began to create training and employment opportunities for themselves as service user trainers and user workers, where their lived experience was valued as an asset for new kinds of support and other roles and relationships.

However, these now seem some distance from the professionalised psychiatrised

meanings that have come to dominate ideas of peer support, increasingly formalised into the role

of 'peer support worker'. Instead of being based on an alternative user-led paradigm challenging

psychiatry, such roles seem more and more to be framed as lower paid ancillary jobs

incorporated into the prevailing values, ideas and structures of psychiatry. Instead of being part

of an enterprise offering an alternative to the psychiatric system, they occupy an increasingly

ambiguous role as an acceptable face of the system for patients entering it, with minimal say and

control over it or their role (Penny and Prescott, 2016; Penny, 2018).

Recovery

The third of these key terms and ideas I want to discuss, recovery is one that I have never

been able to align myself with, although it is argued that it had its origins in the service user

movement – even if subsequently co-opted. For me it is an unhelpful and unconvincing an idea

as being 'cured'. I appreciate that its use has been justified in terms of challenging the historic

writing-off of mental health service users as permanently damaged, dependent and

unreclaimable. Yet we know that conventional wisdom is difficult to justify. Even in the

nineteenth century, inmates were released from asylums, some organisations then like UK

Together (formerly the Mental After Care Association) rejected such assumptions as of course

did pioneering institutions like the Retreat (Rogers and Pilgrim, 2001).

I remain unconvinced by this rationale and recovery has never seemed a helpful concept

for me. It is difficult to see how it is separable from a bio-medical model. It does not take long to

work out that if someone is seen as 'recovered', then the support they have received may also be

seen as no longer necessary. I have perhaps also been influenced here by my involvement in the

disabled people's movement. There such a medicalised individual idea has long come under

challenge. The movement has developed a social model of disability, which highlights the

barriers facing disabled people in response to their perceived impairment. Why would it make

any more sense to think that a mental health service user functioning more equally in society

could have their support curtailed than to think that a disabled person could have their

wheelchair or other aids removed? The reality has been that the idea of recovery has been bound

up in neo-liberal psychiatric thinking with 'restoring' service users to employment.

Turning our ideas against us

A constellation of ideas including recovery, but also 'resilience', 'independence',

'empowerment', have all been developed within western psychiatric systems, based on

prevailing neo-liberal values of:

- Individualisation and individualism

- 'Privatising' distress; treating it as a private family matter

- Reducing state intervention and support services

- Charging for help or intervention

- Equating social inclusion and cohesion with being in employment

Not only has neo-liberal discourse suborned the meanings of progressive ideas developed

by survivor and other movements, like empowerment, autonomy and

inclusion, but it has also used them to undermine and withdraw key supports formerly available

to them.

Thus, in the UK, for instance, a particular target has been day provision for mental health service users/survivors. Such centres have been closed down wholesale (Beresford and Bryant, 2008). They have offered service users safe spaces where they could feel secure, have contact with other service users, get meals and drinks, have access to activities, occupation and recreation and pathways to gaining skills and opportunities. But policymakers have used user movements' arguments for desegregation, mainstreaming and social inclusion to justify such closures, when what they mainly result in is people being cut off on their own within their own four walls or even left homeless. But if this policy is intended to restore mental health service users/survivors to the mainstream, 'participating more fully in society', then I imagine that they are expected to be spending time instead – when not in suitable (or unsuitable) employment - the main driver of the policy - in public spaces like cafes and restaurants.

I love spending time in cafes, doing work like this in them, or people-watching. But I also know what an Americano or cappuccino costs and that there are strict limits to how long many such businesses will let you sit over just one coffee. How that is meant to work for mental health service users/survivors living on benefits or low income, I'm not sure. How comfortable, safe or welcoming such environments may feel to some mental health service users/survivors, unsupported, perhaps in distress and like a number I've seen bearing consequences of psychiatry's over-reliance on drug treatments, like tardive dyskinesia, I don't know. But well run, outward looking day centres can be both a sanctuary and a jumping-off point for other things.

From the undermining of our ideas to the theft of our alternative models

However, it is not only survivors' ideas that neo-liberal psychiatric policy has fed back to us in diminished form. It has done the same with our alternative models of policy and support. I first got involved in survivor organisations in 1987. While earlier iterations of survivor collective action can be traced back decades and in some forms even far earlier, my involvement coincided with the flowering of mental health service user-led action. Looking back I am struck by how quickly it developed and how rapidly it identified radical new forms of both engagement and support, especially since mental health service users/survivors have long faced particular barriers and exclusions because of their perceived irrationality, threat and dangerousness. Ideas and schemes for new forms of support for people in distress emerged very quickly. The fact that they seemed to develop almost fully formed reflects the way that organisations like Survivors Speak Out internationally brought mental health service users/survivors together to develop their own clear principles and values. These emphasised people speaking for themselves, supporting each other and holistic understandings of people's experience and difficulties.

User led support schemes emerged speedily. Already by 1993, the pioneering Australian survivor activist Mary O'Hagan had visited and was reporting on a wide range of such user led schemes in the USA, UK and Netherlands (O'Hagan, 1993). By the millennium, a major user-led research project in the UK into user led services and support across disabled people and mental health service users was reporting in depth both on the significance of such programmes and also how their service users particularly valued them (Barnes and Mercer, 2006). Such schemes included user-run help and advice lines, crisis support and houses, user training and trainers projects, day services, housing and employment projects, direct payment support schemes and much more. These were particularly pioneered by user/survivor led organisations (ULOs) and a

network of such organisations began to develop, at one point supported by an explicit UK government strategy.

What I find particularly disturbing, having both witnessed and charted this pioneering and transformative development over at least 30 years, is how few such user controlled schemes and projects there now seem to be internationally. Instead a pattern has emerged of non-service users and their organisations purporting to offer such provision and securing the funding – despite lacking the skills and experience to provide it – and of user led organisations failing to secure funding or losing it. This has meant that often where services have been set up badged as 'user-led' or 'centred', they have simply been underpinned by the same old bio-medical thinking and diagnosis-based approach. This has been a measure of the much greater visibility, power, perceived legitimacy and authority of more traditional charitable organisations and of the continuing discrimination faced by ULOs. The latest evidence worryingly highlights both that survivor led organisations, for example, in the UK, are seriously declining in numbers, while the same pattern is apparent for ULOs more generally. While some new organisations are emerging, others are having to close or downsize. Over an 18 months period from 2015, more than a quarter of survivor led organisations in England had closed down (Yiannoullou, 2018). The rhetoric in the UK, with which I am most familiar, has been of encouraging non-state organisations and interventions, but this has only advantaged traditional charities and large for-profit organisations.

All the neo-liberal talk of 'welfare pluralism' has opened few doors for service users and these have rarely stayed open. Instead different non-psychiatrising approaches to offering insight and support largely seem to have been stifled over a generation, despite all the efforts of survivors and our organisations. This has been at enormous cost, both individually and

collectively for mental health service users/survivors. We have both been denied opportunities to

gain valued help and our efforts to contribute and help each other squashed. The effects of both

are not difficult to imagine for those concerned. The neo-liberal psychiatric system has so far

shown itself to have an enormous capacity to resist attempts to

reform it, both from within and outside, as well as to subvert opposition and the alternatives it

offers.

Survivors, research and knowledge production

However, I do still see from my years of experience as both a survivor and activist, two

beacons of hope which continue to encourage me. First though, I would like to touch on an issue

that for me has increasingly emerged as having particular importance in our struggles to

challenge western neo-liberal psychiatry. I am referring to service users' contribution to research

and the production of knowledge. Research has been the site of one of the most complex and

contentious struggles between survivors and neo-liberal ideology. As a survivor researcher, it is

one that has particularly engaged and affected me, but I think it is of critical importance for all

survivors because of its implications for the development – or otherwise - of our own

knowledge(s).

The origins of this struggle may be seen to lie somewhere else – in the struggles of

feminists and disabled people - to challenge what some have called 'epistemic violence' and

exclusion, from the 1970s and regain control over their experiential knowledge – the knowledge

that comes out of people's lived experience. The UK disabled people's movement condemned

existing disability research in the 1970s as biased and on the side of the service system that

controlled their lives. To counter this, they developed their own 'emancipatory disability

research' which prioritised the equalising of research relationships, the empowerment of disabled people and the achievement of social change to support their rights and needs (Barnes and Mercer, 1999). The survivor movement developed survivor research along the same lines. At the same time existing research structures began to show an increasing interest in involving research subjects in its process, framed in the UK in terms of 'public, patient involvement' or PPI. For a time there has seemed to be some convergence between these two developments. But increasingly tensions have emerged between the consumerist/managerialist aims of such involvement in much mainstream psychiatric and other health research under neo-liberalism and the emancipatory goals of mental health service users/survivors. Thus PPI is coming under increasing attack as 'centered on a construction of the abstract, rational, compliant, and self-managing patient' under neoliberalism (Madden and Speed, 2017; Rose, Carr and Beresford, 2018). Neo-liberal social policies, as we have seen, have also come in for broader condemnation for isolating service users by causing the closure of day and other support services and the loss of safe public space, seeking instead to force mental health service users into employment, regardless of how suitable that might be for them (Bryant et al, 2010).

At the same time, for me and other survivors, involvement in research/survivor research is critically concerned with extending and sharing our knowledge base to challenge psychiatric dominance and advance our own ideas, rights and interests. This is especially important, put simply because while PPI may be essentially concerned with recruiting mental health service users in the service of psychiatric knowledge – which may not be in our best interests - survivor research is concerned with advancing our own knowledge, the critical foundation on which all else we can do rests. There are fundamental conflicts between these two positions and speaking from my own direct experience, they are manifest in every aspect of the research process.

This extends from the 'peer review' process and the kind of judgements that can be imposed on survivor researchers, to the discriminatory way in which research funding is allocated, resulting in the continuing marginalization of survivor research and researchers. You certainly need 'resilience' to cope with this!

In 2006 Shaping Our Lives, the UK disabled people and service user led organisation and network published a study which highlighted the relationship between the development of user knowledge and support for user led organisations. This showed that barriers to service user networking were created by the marginalisation of ULOs which in turn inhibited the development and sharing of user knowledge (Beresford 2006). Since then another research and development project by Shaping Our lives has evidenced the way in which diverse involvement is restricted. It identified big barriers in the way of five groups, but also ways to overcome them. These key groups of service users are excluded according to:

- Equality issues; on the basis of gender, sexuality, ethnicity, class, culture, belief, age, disability and so on

- Where they live; if they are homeless, travellers, in prison, in welfare institutions, refugees and so on

- Communicating differently; they do not speak the prevailing language, it is not their first language, they are deaf and used sign language, etc

- The nature of their impairments; where these are seen as too complex or severe to mean they could or would want to contribute

- Where they are seen as unwanted voices; they do not necessarily say what authorities wanted to hear, are seen as a problem, disruptive etc. These includes neuro-diverse people and people affected by dementia (Beresford, 2013).

The large scale operation of these barriers means that the knowledges of many service users are routinely excluded from consideration.

There are also other ways in which user knowledge is marginalized. Here are a number of expressions of such exclusion and discrimination which I have routinely faced and know other service user researchers/organization experience in relation to research funding:

- Being consulted by funders (sometimes without payment) to gain our expertise and then funding awarded to individuals or organisations they feel more comfortable or familiar with;

- Asked for help and advice by those who are awarded the funding, having lost out to them

- Service users working with non user-led projects get funding while those operating within democratic user-led organisations don't;

- Leaving flexibility and space in research design for participants to have a real say in shaping it and then being rejected for not being 'specific or detailed enough' despite having a proven track record;

- Research organisations enormously advantaged in research bid process because they have access to support departments in developing proposals which ULOs lack;

- Academic and other organisations establishing superficial or unequal research relationships with service users and their organisations to secure funding for supposedly participatory, partnership or user-led projects

- With research funding increasingly restricted under neo-liberal regimes, calls are more and more narrowly tied to government agendas, which service users know are unhelpful and unworkable;

- An increasing emphasis on research 'impact' interpreted in narrow economistic terms rather than in terms of improving the lives and life chances of service users as emphasised by survivor research.

Beacons of hope

And now I want to turn to my two 'beacons of hope'. The first is perhaps the most important development that has grown out of this search for new understandings of distress which places value on the lived experience and knowledge of mental health service users. This is Mad Studies.

Mad Studies

Mad Studies brings us back to the issue of language with which I started. 'Mad' continues to be a contentious word, not surprising given the abusive, pejorative and devaluing way it has long been used. It is contentious still among survivors too. But it is a term with which I can identify. I think it has been deliberately revisited in this way to show a determination to reclaim the word by those who identify as service users, as experiencing distress and their allies. I feel Mad Studies offers real hope for the future. It is exciting because of its potential to bring about positive change (Le Francois, Menzies and Reaume, 2013).

As I have said, I believe the rise of right wing politics, combined with the increasingly assertive expansion of the psychiatric system have worked to stifle alternative ways of

understanding and responding to distress. They have formed a powerful informal alliance that focuses on the individual and her or his responsibility so-seen for their problems and the assumption of things wrong in our heads.

I believe Mad Studies has an unprecedented and unparalleled potential to challenge this unhelpful and damaging status quo. It offers a real possibility to move on from a narrow medicalised individualising model; to link us up in our different roles and standpoints; to give equal priority to user knowledge and experience taking us beyond over-reliance on professional and medical authority and expertise.

Nobody owns Mad Studies. We may all understand it in different ways, but for me what is critical about it, what defines the key elements of mad studies is that:

- First, it is definitely divorcing us and itself from a simplistic biomedical model, making possible a necessary rupture from it. It allows other understandings and disciplines to come into it, instead of solely medical dominance – sociology, anthropology, social work, cultural studies, feminist, queer, disability studies, history, everything.

- Second is the value and emphasis it places on first person knowledge – centring on the first person knowledge of everyone, not just those psychiatrised. If you want to talk about yourself, then you have a right to; it is ok to include yourself. This is positioned/situated research – you can't just be talking from nowhere, as if you had no place in the proceedings – as it has been in psychiatry.

- And finally of course Mad Studies treats survivors' first hand knowledge with equality. But Mad Studies values and has a place for all our first hand experiential knowledge; that's why such a wide range of roles and standpoints can contribute equally to Mad Studies if they are happy to sign up to its core principles. It isn't only us as survivors/mental health service users, but allies, professionals, researchers, loved ones, and so on, This is a venture we can all work for together in alliance. So it includes the experiential knowledge of service users, the practice knowledge/wisdom of workers and the knowledge from those offering support, of family carers as important bases for future research and development (Russo and Sweeney, 2016).

Gap-mending

Gap-mending, my second new idea, is one pioneered in social work education which builds on the idea of valuing people's experiential knowledge. It has been developed by PowerUs, a partnership of social work educators and service users and their organisations and already involves twelve countries, within and beyond Europe. PowerUs seeks to develop methods of mutual learning in order to change social work practice to be more effective in supporting the empowerment of marginalized and discriminated groups in society. (http://powerus.eu). This includes people as mental health service users/survivors. The gap-mending process began at Lund University in Sweden in 2005 as a method of teaching that brought service users and social work students together to learn together on as equal terms as possible. The idea is about bridging divisions between service users and social work students in their learning through new approaches to user involvement. It also represents an alternative approach to the increasing emphasis under neo-liberal politics on graduate and elite/fast track

approaches to social work education, giving value to 'user knowledge', rather than just academic

qualifications.

People 'meet as people' on gap-mending courses; service users get formal recognition

and accreditation for the skills they offer as well as the skills they gain. Social work students who

also have 'lived experience' as service users are valued for it and can share it if they wish to.

Perhaps most important is the building of trust and understanding between service users and

would-be social workers which is likely to have a profound effect on future relations and practice

between them (http://powerus.eu/news/the-photo-exhibition-experiences-matter/)

Key gaps that the approach has identified include between needs and resources; the priority

social work demands and the priority it is given; service users and providers, 'expert' and

experiential knowledge; social work education and practice – and researchers and research

subjects (Askheim, Beresford and Heule, 2016).

Comments from service user/students in a PowerUs publication, 'Experiences Matter',

exactly reflect my own feelings and what has led me to write as I have done here, for example:

When I started studying Social Work I thought I was vulnerable because of my personal

experience as a service user. Now I know that my experience is my strength. I want to inspire

students that everything is possible as long as you believe in yourself!

Annelies

I've learned more in the streets than in any classroom. It was my own experience of

mental health issues and crime that motivated my interest in helping others.

Roy   (http://powerus.eu/news/the-photo-exhibition-experiences-matter/)

My involvement in Mad Studies and Gap-mending has made me feel that they are two

hopeful ways in which we can advance our own agendas and resist the

tendency of the psychiatric system to co-opt and undermine them. Of course these two initiatives

are themselves susceptible, but both encourage collaboration, both put experiential knowledge at

the centre.

Writing this has been a further reminder to me that our collective struggle has to engage

with complexity and uncertainty. Such a world of ambiguity and conflict demands we build trust

with each other and show ourselves trustworthy.

The struggle for survivors' rights and as part of that survivors' knowledge, is an on-going

one. While there were early achievements and successes, like the *Strategies for Living* project

(Faulkner and Layzell, 2000); Mary O'Hagan's *Stopovers On My Way Home From Mars*

(O'Hagan, 1993) and the publication of *This Is Survivor Research* (Sweeney et al, 2009), the

years since have hardly been ones of unopposed progress. The pioneers of survivor activism and

theory building have been joined by new generations of campaigners and writers working to

change understanding of madness and maddened people. It is important to support them. They

have maintained earlier struggles as well as opening up new domains for change and resistance.

This extends to issues of ethnicity, difference and intersectionality; (Atkinson et al, 2008; Meerai

et al, 2016; Luthi, 2016) and of inclusive survivor research and knowledge production (Russo

and Sweeney, 2016).

Writing this article has led me to reflect on both my own identity and situation as a

survivor and that of those others more recently involved in such struggles. It has confirmed my

view that such involvement is key. I also think it is important that we position ourselves to help

people know where we are coming from and what influences our viewpoints and experience

coming to this discussion. As I touched on at the beginning of this article, I have a mixed ethnic background and identify as Jewish, part of the Jewish diaspora – I have strong sense of Jewish ethnic identity but of course am deeply conscious of strong conflicting issues there with being ethnically Jewish but rejecting Zionist nationalism. It is also very important to me that I am a psychiatric system survivor and have long experience of living on welfare benefits. Since childhood I have felt uncomfortable with dominant models of masculinity which seek to embody inequalities and exclusions that I reject.

I have been fortunate as a survivor to have achieved all that I have managed to; having a career, being involved in making change. My grandparents came to Britain at the turn of the twentieth century in the wake of one of the appalling anti-Jewish pogroms then taking place in Eastern Europe. They came as refugees, with nothing. My grandmother never learned to speak English. My mother left school at 14 and worked in a sweat shop. Yet here am I, someone brought up in a lone parent family, who got a grant to go to Oxford University, was promoted to Professor working at Brunel University London and who was awarded an honour for my work, which I received from the Queen (Beresford, 2016, p361). There is no question that this was possible because I was a beneficiary of the post war UK welfare state. Since then neo-liberal policies have rolled such provisions back in the UK and internationally and those coming after people like me, have had few of the advantages we had. Amiel Joseph's discussion looking 'beyond intersectionalities of identity' highlights how problems of privilege can be magnified under the free for all of neo-liberalism (Joseph, 2015).

Mad Studies and gap-mending both place a premium on building trust and equal relationships by being clear about their principles. Our challenge is to be as clear and honest as we can about the threat to them from neo-liberal ideology and its increasing alliance with

individualising and pathologising psychiatry and to work inclusively to articulate and minimise

this threat. These struggles may be yet harder in the future, but we now have a history, a

momentum and a strengthening and diverse collectivity to take them on together.

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