Co-building Opportunity

We will continue to campaign and to support a vision which will see education at the heart of change within a world which is truly empowering, where individuals can decide on and participate in the policies and personal decisions which affect their lives meaning they have the choice to pursue a life they deem fit for living.

The Manifesto, 2021

Summary

At WARM, we are committed to developing a community place within which all individuals who experience mental trauma, disadvantage or otherwise hard times, are respected, valued and are represented in a safe, true and trusted way. We envision this place to contain appropriate support with services available for those who need them. This place, if it is to be truly empowering, must also mean that individuals, as well as the group representing them, can feel empowered to decide on and participate in, the policies and personal decisions which affect their lives helping them to pursue a life they deem fit for living.

In this place we in particular want the principles of a concern for the human rights of all people respected as well as those with a mental illness. People with a mental illness can no longer be excluded from exploring and deciding on the processes which fundamentally help heal them.

We want to see that personal respect is adhered to at all times.

We want to see that relationships are premised on openness and not hierarchy or 'professionalism'.

We want to see that engagement in activity is useful and is valuable to the person – activity that is not tokenistic.

We want to see that an individual's social, spiritual and emotional wellbeing is supported.

We agree that medicine has a place – but it is not the only intervention to consider in supporting someone in trauma.

Bessel Van Der Kolk supports this view when he argues, convincingly, that the brain disease model of mental illness overlooks four fundamental truths:

1. *our capacity to destroy each other is matched by our capacity to heal one another – restoring relationships and community is central to restoring well-being.*
2. *language gives us the power to change ourselves and others by communicating our experiences, helping us to define what we know and finding a common sense of meaning.*
3. *we have the ability to regulate our own physiology including some of the so-called involuntary functions of the body and brain through such basic activities as breathing, moving and touching.*
4. *we can change social conditions to create environments in which children and adults can feel safe and where they can thrive.*

Being a patient – or worse, a service user – being isolated from carrying out a validated human role separates us from our inner-self, from the healing process, from our communities which in turn can alienate us as human beings. What we have come to realise is that the single most important 'thing' for good mental health are safe, social and community connections which help build and support meaningful and satisfying lives.

The following manifesto, we believe, sets the foundation for this place and these principles to be realised.

The manifesto of the Widening Access, Research and Mentoring (WARM) community group

1.

Why this manifesto?

Service providers, policy makers and people from many different organisations are increasingly calling for 'service-users' to 'co-create' and to 'co-produce'.

In this way, such 'service-user' activity is now seemingly destined to support a world of service provision – provision which is decreasing, because it is under-resourced and is misunderstood. However, if 'service-users' are to meet this destiny of a middle ground of design, delivery and development of services – if they are to become what is otherwise claimed as *equal* partners in the delivery of services, then it is fundamentally important that we move away from the negative connotation a 'service-user' status bestows. This way we can develop a more detailed understanding of a community wide model of co-production, social engagement and critical confrontation.

The key roles for achieving this new found critical confrontation must also become a social movement – of human rights and the right to participation – with a new set of ideas and a new agenda – a new paradigm – because this can be the only way forward in meeting the challenges of service design and delivery.

And we can see this need when we discuss the current state of co-production. It is a process which seems to *invite participation into what is already.* This means any critical engagement is already negated in favour of supporting the status quo approach to participation in service design. If we are to have a truly challenging and community focussed approach to service design and delivery, then we need to change any service specific and narrow approach to co-production.

Otherwise, the creative space for challenge and for debate – the middle ground for change – will continue to be removed and replaced by a separated 'partnership' of 'equal' members of a team where those engaged, by nature of their invited co-option – speak the language of what exists – not the optimism of what might be.

We need to turn this language of what exists in on itself – work with people and communities who know and experience this language – and to engage with new and innovative and exciting ideas for positive change which challenge and shape the language *for what could be* – this is why the challenging language in this manifesto is, we believe, now urgently required.

We want to pursue the growing need – to *critically* engage in evidencing, sourcing and developing groups, who recognise their own needs for organising and for forging partnerships for this critical activity.

We want to engender a reflexive, empowering role – one which is achieved not by the well-meaning organisation who will 'empower' the 'service-user' – but rather empowerment and independence being recognised, taken from the organisation and brought to communities.

We want a social movement which is not *represented* by well meaning 'partners'. **We** want to forge these partnerships on the efforts of shared ideas, on the flexibility and strength of shared groups; on shared, relational terms; on shared demands; this, we believe, is why this manifesto is timely.

2.

We really do live in exciting times

Great strides have been taken in medical advancement towards tackling some of the most enduring illnesses humanity has to face.

Yet, the approach to how we both understand and support mental health and wellbeing; disadvantage and social justice in the UK (and elsewhere) still seems to struggle to interpret not just the suffering individuals experience – which can be some of the most devastating types. There remains a dehumanisation which sees a reluctance by the many to recognise the skills, the passions, the humanity and the person resting at the centre of these struggles.

We are very clear in this manifesto – good mental health is fundamental to a good and desirable, healthy lifestyle and a quality of life.

Yet, despite the increasing call to 'co-create' a terrain upon which a greater level of 'service-user' involvement can be gained – challenging, as it can, the physical (psychological) determinants to mental illness and social suffering; we argue that other factors such as those at the structural level – poverty, stigma, social isolation and disadvantage (to offer but a few) seem to be left to somehow meld into the background of service design and construction. We are not on our own in this thinking because as Roger Gromm (2009) correctly observes, "for nearly every kind of illness, disease or disability, 'physical' or 'mental', poorer people are afflicted more than richer people: more often, more seriously and for longer – unless of course, they die from the condition, which they do at an earlier age (p.96). This attention to 'social ills' is missing in service design and as such remains a baffling omission from

this 'new wave' of service led optimism. This manifesto does not make such a mistake – we understand from the outset the social and cultural influences on mental health and wellbeing.

Make no mistake - we welcome positive and optimistic attitudes – but we are also cautious to point out that unless we have a critical and active understanding of the social as well as the biological determinants of poor mental health – side by side, then these optimistic approaches to 'service-user led' monitoring and evaluation of service provision will only ever remain partial. Partial because the self-fulfilling, self-abasing nature of mental trauma allows stigma and discrimination to remain crippling, destructive and isolating forcing the *rights* of the person to remain opaque.

We cannot ignore that as humans – our humanity, our relationships and our social interactions shape our minds, our brains – our health – and gives substance and meaning to our whole lives. This makes social support a biological necessity and not an option – and this reality should be the backbone of all prevention treatment (Van Der Kolk p.64)

We welcome the discourse which asks for a partnership approach to adequately determine what services should be provided and where – but situating the 'service-user' central to decisions related to their recovery is contentious if this centrality does not tackle the inherent structural and perceptual inequalities many are facing alongside their mental ill health.

Van Der Kolk (2014) so rightly observes that "social support is the most powerful protection against becoming overwhelmed by trauma and stress; that truly being heard and seen by people around us,

feeling that we are held in someone else's mind and heart" (p.79) helps keep us mentally safe and cannot be experienced through a prescription.

In addition, these social supports are hard-earned and complex capacities which can often be lost 'in the system' but ones we must regain. Whoever supports this manifesto will remain at the centre of this critical confrontation to the *social inequalities* faced at all possible points of contact.

We are not pessimists – we are, in fact, the direct opposite.

We are convinced we are now at an exciting juncture where a new culture – a different understanding of not just our mental illness, but the routes through which we can make effective changes in our communities, are recognisable. We are convinced that if we unite with other people – if, like other groups, we can become popular activists in determining what our future might be, then we too can begin to challenge and to change the social system within which our futures lay.

We can make these changes not as a lone voice but rather as a recognised, collective voice which refuses to resign ourselves to 'our fate' but rather sees the future in our desire to be the precursors to change.

William Tuke saw this in his moral reforms of the 1790's – we must see it still. This manifesto pledges to move away from representation and to bring these groups together as a unified voice, a unified model of activity which represents itself in its own and fullest meaning.

3.

The language and practice of inability - Reducing skills and abilities

We recognise that 'service-users' (otherwise known as people) are very well *represented*, but we are not convinced, any longer, that this representation meets the real challenges we face as people.

While we believe the skills, the passions and the vision exist among us to represent ourselves – the question we have to pose is this;

> *Are those who claim to represent the interests of 'service-users' really able to carry through an agenda and an action plan to meet our needs as people?*

We are not claiming our representation is cynical, powerless or simply unable – instead, we claim that all the factors required for such an equal partnership have not been adequately *explored and developed*. Hence why we are proposing critical confrontation to challenge and to take the 'service-user' ground for ourselves, beyond the current forms of representation and beyond a current narrative which can never articulate our needs and our vision while it remains devoid of discussions of our rights as humans.

Instead, we need to explore our own language which fully articulates the real sense of opportunity available. This language needs to be presented in our own terms so as to influence changes at both the 'top' and the 'bottom' of our social ladder. This is why this manifesto pledges that we will work to redefine what engagement and fairness actually means.

4.

What type of vision do we have?

Some people say we need a fairer way to engage in the 'mainstream'. We would agree – but only in part - we (whoever we are) should not be the only ones to change

to meet the demanding world we now live in.

If we are to co-build our world then this requires a different way of engaging, a different language and understanding of what this engagement might look like – but at *all levels of our social structure – medical, social, political as well as personal.* The change required, then, has to be discussed, recognised and challenged – across environments – but we have to be able to both understand and to articulate for ourselves what our terrain – our field of operations looks like. It is not simply up to us, alone, to change.

Some people talk of 'empowering the service-user'. We say thank you very much for the kind offer but we recognise that this remains a passive relation.

Empowerment is not given – it is negotiated, found – taken, even. If we want to recognise empowerment, then we cannot *be handed this on a plate* – we have to take the tools of empowerment – with our skills and our passions, our beliefs and our reasons for existence – and use these for our own sakes to shape a language and a vision which truly meets our demands. Thus, we want to see the vast array of skills which we have, used to good effect, to build opportunities for movement, for play and for joyful engagement which will be the forces to take back an empowerment which we will define and which we justly deserve.

Some people say let's go 'co-create' and 'co-produce' to reduce stigma (external and internal) and to make services more suitable for you – the users. We say that we are absolutely committed to co-creation and co-production – but not the sort that seems to represent us.

Once more, we see a passive relationship between our 'equals' who offer very well

meaning opportunities to 'join in' and to 'co-create' and 'co-produce' a language and a meaning among people who are otherwise referred to as our partners. But we ask this – did we choose these partners from the outset? Did we design the programme? Did we endorse the language? Do we truly have an equal relationship? What sort of equality are we really talking of here then – am I really equal to the professional? Is this really our vision? Do they even know who **I** am?!

We obviously recognise great examples of where this co-creation works – we offer our own as a case in point – but our argument here is we need to see a unity of thinking, of approach and of critical contestation which brings these critical movements together – in both critical activity and in critical thinking and it is then we can begin to unify our needs and how we articulate those needs.

We require a more fraternal approach to service design and delivery – which recognises cultural differences but is premised on a universal practice of partnership and solidarity and a widely diverse model of social engagement.

We want to forge common ideas and aims – goals and aspirations – as one unified voice among the many – a language and a practice of discovery and playful but critical ideas and discussions – then we can participate in co-creation and co-production – then we can claim our language and our representation; then we can say we are living among the social mainstream.

Some people refer to us as 'the service-users'. We say that in an increasing and competitive market for the 'service user' we find that the language of 'service-user' is increasingly objectifying.

If our only reference point – our only identifier – our only connection to the world becomes that of 'service-user', as object and as a commodity for sources of funding, then our route to an equality of co-creation is already potentially negated and undermined.

We have many other titles we can share – but what we are, really, *is real people with real passions and real ideas and rights* – with the skills to match. While we are separated from our world of living and existence – while we are *negatively reflected* in such a sanitised term as service-user (or the many other labels we seem to inherit) – while we remain social and medical oddities – then we continue to remain subordinated and reduced to 'service-user' objects commonly traded 'among our equals'. This simply keeps our identity fixed and stubbornly resistant to change.

Some people say they want to develop new opportunities for engaging and for change. We say yes, naturally, we are in absolute agreement and see this as a welcoming shift in thinking and in focus from the one which otherwise sees us as a deficit – or as a drain – on our community and on resources.

But these new opportunities cannot be limited – they cannot be confined just to service development – or to 'arts and craft' – or to other menial 'things' because we have a whole set of opportunities out there 'to do things' – we can define and we can deliberate on our own behalf what our ideas for social engagement are and we can take this forward with you, ourselves.

But if we are to achieve this, we know we will face challenges and resistance which _we_ need to be able to both confront and defend.

This means for these opportunities to really be new and accessible, the emerging need for recognition of our role, our strengths, our determination and our capability to be seen, listened to and heard in this development, has to be paramount.

We are only limited by our desires and our imagination – our imagination is flush with the desire for total change.

5.

How we propose to meet these people in the future - co-building opportunities?

We are not a separate entity from you, 'the social mainstream' – we are one and the same.

We don't require special treatments – nor do we require special services – *what we say we require,* as a minimum, to meet our representatives and the challenges ahead in the middle ground, are as follows.

The freedom to critically confront service planning

Training to meet the demands of participation (co-creation and co-production) in an unfamiliar terrain.

We wouldn't expect someone to be automatically prepared for the challenging roles we foresee without suitable education and training. *So we say send your managers and your leaders to us and we will train them in how to understand this terrain – the perspective of the person who will access the opportunities on offer. We know what we want – you just need to understand how we achieve this.*

Partnerships of like-minded people. We are not any longer willing to work in passive relations – we want to struggle and earn the opportunity to forge equal partnerships, relationships and friendships with people who are willing, humble but passionate to do what is right – whoever

they are. No one person is better than us, – nor we better than they.

Empowerment which is earned, not received – we cannot nor will not accept empowerment being offered – we have to struggle and earn this to be able to critically determine what empowerment might look like. For this, we have to create a new culture of social engagement where the terms of engagement are very much established by those engaging.

Recognition that, for some people at some times, the severity of their mental health issues, often compounded by social and other difficulties may preclude them from taking an active role in this engagement.

The strength of the groups we offer is that they can, in such circumstances, provide representation, support and advocacy to all its members, based on the knowledge of terms of engagement previously determined by all members. This will be a place of safety and feeling safe with others which is probably the single most important facet to a person's mental health.

We want a place where:

Dignity and personal respect – is a human expectation. We are not to be treated as oddities. Our experiences – our feelings of our world is ours – it is not odd

Humility – we are all the same – there's no reason to be seen differently – whatever role/position we hold.

Safety – we all want to feel safe – and sometimes, in our most vulnerable states, this is more important than other times – it's an essential human need.

Supportive – we can be and are supportive of others – we expect the same – not patronising support – but emotional and personal guidance for moving to new

places of exploration. It is our human right, surely, to feel valued and supported.

Challenging – if surviving our environment and lives does not offer meaningful challenge – then what is the worth of continuing to survive. We want meaningful engagement – not just jigsaw puzzles.

Meaningful relations – that encouragement, support, basic dignity (not stigma) friendship are basic human traits – we want to see this in our treatments.

We have personal needs to:

Forge new opportunities for engaging in meaningful activity in our social world.

Be recognised as a significant human being – not a drain on our community

We recognise the political field for:

change at the 'top' not just the 'bottom' – the idea isn't a new one.

Training new people for socially significant roles – across all sectors – not just within the 'mentally ill'.

Redesigning policy to recognise real, popular engagement and to foster critical language.

Stigma is personal and social so we need:

Critical activity not just critical words – taking social action and social critique forward – not in the terms and the ideas of what exists but rather what might be. This is not the time to reduce the imagination to limits but to let the imagination soar in a world of limitless possibilities.

To rethink ability and capability in a world of challenge so as to disrupt comfortable perceptions and common understanding of the 'service-user'.

To reform public action and debate in a language we deem suitable for this worthy

cause and *to regroup* as a challenging entity.

Sponsors;

We believe there is no place for opposition to these claims – for these are the commonly agreed among us – these are the basic rights we eschew.

If we are to truly achieve the *right to* live – with or without a mental illness, then we too must take the responsibility for designing what this might look like. But for this design to be effective, we must too have the full freedom to co-design – and this is what we will work for.

Final summary

The WARM team are determined to deliver change through education – at all levels of engagement. It is with this is mind that we ask all those who read this manifesto and support the vision to speak out and to challenge the range of discrimination, stigma and injustice.

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