



# Members' Manifesto 2019

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- We aim to:**
- 1. Campaign against the injustice and harm caused by cuts to public funding and welfare benefits.**
  - 2. Challenge the abuse and coercion that continues under mental health legislation and work to ensure that people understand and can enforce their rights under the UNCRPD.**
  - 3. Actively promote the need to work with us in decisions about strategy, commissioning and how services are provided, as well as the need for services to be user-led.**
  - 4. Challenge personal, institutional and structural inequalities, injustices, disadvantages and discrimination for everyone with experience of mental distress/trauma.**
  - 5. Promote people's right to informed choice so that people are in a position to understand their difficulties in whatever way they choose and to access the support that they find best.**
  - 6. Promote the validity and vital role of survivor knowledge and research.**

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The National Survivor User Network (NSUN) is an independent charity led by survivors and **service users**. It connects **people with lived experience** of mental distress and gives us a stronger voice in shaping policy and services.<sup>1</sup>

### OUR VISION

Our vision is for the lives of people who experience mental distress, discrimination and disadvantage to be better.

### OUR MISSION

Our mission is to create a diverse, inclusive and influential user-led network with the strength to challenge inequality and improve lives.

### OUR AIMS

- To create and strengthen links between individuals and groups.
- To support and promote user-led groups and initiatives.
- To influence and inform policy and decision makers.

### OUR VALUES

- Solidarity – our network recognises commonality of interests and experiences, and facilitates mutual support.
- Equality – we believe all members should have equality of status, rights or opportunities.
- Integrity – we strive to express the views and experiences of our members in an unbiased and unfiltered way.
- Diversity – we understand, recognise and value difference - our different backgrounds, experiences, ethnicities, beliefs and abilities.

# Members' Manifesto 2019

Our Members' Manifesto is an evolving document. Since 2013 we have been gathering the views of our members and prioritising issues - initially in the form of a 'top ten' list of issues which was then developed into a manifesto. The Members' Manifesto 2019 updates the 2017 version following our 2018 Annual Members' Event and AGM, and a member survey. The document draws together our aspirations, intentions and key demands with regard to policy and practice. It is not exhaustive but represents the major priorities expressed by our members.

### Why is this manifesto different?

This document outlines the key issues in mental health from the perspective of people with lived experience of mental distress. That is what makes it unique. It conveys the views and experiences of our members and reflects their radical aspirations.

### We want to use the manifesto to:

- a) make our own aims and intentions clear
- b) encourage real conversations between service users, professionals, researchers and policy makers and
- c) help change take place in our services and society.

**It's time for  
service users  
and survivors  
to lead the  
agenda,  
rather than  
responding  
to it.**

<sup>1</sup> Terms marked in bold italics are explained in our glossary at the end of this document.

We are living in uncertain and turbulent political times. The eventual effect of Brexit is still unclear, but brings a strong risk of adding to the number of people who experience mental distress and “weakening the things in society that people with mental health difficulties need to have the best life possible”.<sup>2</sup> Many people’s mental distress needs are still not being met.<sup>3</sup> Funding cuts have led to a loss of advocacy and support services and welfare benefit reforms are having a devastating impact on people.<sup>4,5</sup> The Mental Health Act review recommendations (2018) have also fallen short by fundamentally failing to address human rights issues.<sup>6</sup>

In addition, many independent collectives of service users and survivors are being forced to close. We estimate that about 50 user-led organisations that were previously NSUN members have been forced to close in the last year. This follows a net loss of more than 150 NSUN groups in the previous year. Other user-led networks such as Shaping Our Lives and People First Self Advocacy have also reported on the alarming number of user-led and **self-advocacy** groups that have closed over the last few years.

Our 2019 campaign has been to demonstrate the value of user-led groups in our society and to fight their cause for survival. Our survey of user-led groups across the country showed that organisations are running a diverse range of activities, with many providing a variety of different services including peer support, training, consultancy, arts activities, research and advocacy. The benefits of mutual support, connection and solidarity are often life changing and sometimes life saving for members. However, many groups are struggling to survive or facing closure. Small user-led organisations are losing out to larger voluntary sector charities which involve service users, but are not user-led. Involvement often continues to be tokenistic despite the language of ‘**co-production**’. Commissioners and decision makers often do not recognise the value and unique contribution that user-led organisations make to individuals and communities (e.g. through the provision of **holistic therapies**, talking therapies etc.)

As the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has emphasised, it is important that we keep gathering the direct and authentic voices of people’s personal experience. We need to continue to champion the immense value and powerful impact of the work done by local, independent user groups and organisations.

An important part of this work is to promote fundamental human rights changes. Key human rights are those set out in the UNCRPD, because people with lived experience had an influential part in the content of this Convention. ●

## MEMBERS MANIFESTO

1. Campaign against the injustice and harm caused by cuts to public funding and welfare benefits.
2. Challenge the abuse and coercion that continues under mental health legislation and work to ensure that people understand and can enforce their rights under the UNCRPD.
3. Actively promote the need to work with us in decisions about strategy, commissioning and how services are provided, as well as the need for services to be user-led.
4. Challenge personal, institutional and structural inequalities, injustices, disadvantages and discrimination for everyone with experience of mental distress/trauma.
5. Promote the right to informed choice for people to understand their difficulties in whatever way they choose and access support that is best for them.
6. Promote the validity of survivor knowledge and research. ●

<sup>2</sup> Brown, M. 2019. *There is no new normal: Brexit and mental health in the UK since 2016*. Centre for Mental Health. p.22

<sup>3</sup> Mental Health Taskforce, 2016. *The Five Year Forward View for Mental Health*

<sup>4</sup> Trades Union Congress, 2019. *Breaking Point: the crisis in mental health funding*.

<sup>5</sup> Manchester CAB, 2013. *Punishing Poverty? Sanctions and their impacts*

<sup>6</sup> <https://www.nsun.org.uk/News/reflections-on-the-mental-health-act-review>

## 1. Campaign against the injustice and harm caused by cuts to public funding and welfare benefits.

### What does this mean and why is it important?

People are being failed by the system. Despite government claims of an end to ‘**austerity**’, severe cuts in public spending (especially to welfare benefits and local authority funding) are continuing to have devastating consequences on the emotional wellbeing and physical health of people in the UK.<sup>7,8</sup> Funding cuts are increasingly leading to inadequate mental health services. The National Institute for Health and Care Excellence (NICE quality Standard 14) sets out guidelines for ‘service user experiences’ in adult mental health.<sup>9</sup> It details the importance of timely appointments, empathic staff, shared decision-making, clear information and support options.<sup>10</sup> But we know this is not the experience of many people who use mental health services.<sup>11</sup>

**Sanctions** to end benefits if people do not look for work or attend training courses mean that the poorest people in society are left without money. Benefit claimants are being forced to cut down on food and heating, borrow money and use food banks.<sup>12</sup>

The cuts are having a disproportionate effect on people who are already living on a low income, disabled people and BAMER service users who are already more likely to be living in poverty than most white British families.<sup>13</sup> Cuts to public spending have left many people from the LGBTIQ+ community without adequate specialist or community support,<sup>14</sup> and affected many BAMER and LGBTIQ+ organisations and projects.<sup>15,16</sup>

In 2018, Professor Philip Alston, the United Nations Special Rapporteur on extreme poverty and human rights, gathered testimonials from people across the country. One of the key points he made was on the impact of the government’s cuts and reforms.

*“I ... heard story after story from people who considered and even attempted suicide, and spoke with multiple organisations that have instituted suicide prevention training for frontline staff in recent years. One person said, “The cumulative impact of successive cuts has been devastating. People are coming to me because they are suicidal”.*<sup>17</sup>

There is growing evidence to show that austerity measures in the UK have led to an increase in the number of suicides especially amongst those who have experienced welfare reform.<sup>18</sup> There have been an additional six suicides for every 10,000 work capability assessments done.<sup>19</sup>

NSUN’s position is informed by other user-led groups working in this area who have taken different positions in relation to this issue. For example, the user-led group Recovery in the Bin states that there should be “an immediate halt to the erosion of the welfare state, an end to benefits cuts, delays and sanctions, and the abolishment of ‘Work Capability Assessments’ and ‘Workfare’ which are both unfit for purpose”. Welfare benefit reforms are destroying many people’s chances of living their lives.<sup>20</sup>

This is not good enough. Austerity measures, damaging economic policies,

<sup>7</sup> <https://www.theguardian.com/business/2019/sep/05/has-the-age-of-austerity-really-come-to-an-end-sajid-javid>

<sup>8</sup> <https://www.theguardian.com/politics/2019/jun/01/perfect-storm-austerity-behind-130000-deaths-uk-ippr-report>

<sup>9</sup> National Institute for Health and Care Excellence (2011) Quality standard for service user experience in adult mental health, NICE Quality Standard 14. <https://www.nice.org.uk/guidance/qs14>

<sup>10</sup> See also, National Institute for Health and Care Excellence (2011) Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services, Clinical Guideline CG136. <https://www.nice.org.uk/guidance/cg136/chapter/1-guidance>

<sup>11</sup> Rachel Rowan Olive (2018) <https://www.mentalhealthtoday.co.uk/blog/awareness/the-complaints-i-never-made> Mental Health Today.

<sup>12</sup> Manchester CAB, 2013. *Punishing Poverty: a review of benefits sanctions and their impacts on clients and claimants* [http://www.socialpublishingproject.com/uploads/9/6/1/1/9611868/punishing\\_poverty\\_-\\_sanctions\\_and\\_their\\_impacts.pdf](http://www.socialpublishingproject.com/uploads/9/6/1/1/9611868/punishing_poverty_-_sanctions_and_their_impacts.pdf)

<sup>13</sup> Runnymede Trust, 2015. *The 2015 Budget: Effects on black, Asian and minority ethnic people* [www.runnymedetrust.org/projects-and-publications/employment-3/budget-2015-impact-on-BAME-families.html](http://www.runnymedetrust.org/projects-and-publications/employment-3/budget-2015-impact-on-BAME-families.html)

<sup>14</sup> Davies, M., H. Porter and M. Mitchell, 2016. *Implications of reductions to public spending on LGBTIQ+ and services*. London: NatCen.

<sup>15</sup> McDermott, D. and R. Luyt, 2016. *Still Out There: An exploration of LGBT Londoners’ unmet needs* (LGBT Consortium and Anglia Ruskin University) <https://www.trustforlondon.org.uk/research/publication/still-out-there-an-exploration-of-lgbt-londoners-unmet-needs/>

<sup>16</sup> Taylor-King, S., S. Carr and T. Edwards-White, 2016. *Unkindest Cuts: reflections on destruction and resilience in LGBTQ community-based mental health support*, Asylum, 23(3)

<sup>17</sup> Alston, P., 2018. *Statement on visit to the United Kingdom*, by Professor Philip Alston, United Nations special rapporteur on extreme poverty and human rights, p.17.

<sup>18</sup> Mills, C., 2018. ‘Dead people don’t claim’: A psychopolitical autopsy of UK austerity suicides. *Critical Social Policy*, 38(2), 302-322.

<sup>19</sup> Grover, C., 2018. *Violent proletarianisation: Social murder, the reserve army of labour and social security ‘austerity’ in Britain*. *Critical Social Policy*, 39(3), 335-355.

<sup>20</sup> <https://recoveryinthebin.org/recovery-in-the-bin-19-principles/>



► **social discrimination** and structural inequalities are causing harm to people. We urgently need to work together with other organisations across the country to oppose this.

### We have been doing this by:

- Co-facilitating a 'Deep Democracy' event with other disabled organisation partners on Disability and Employment.
- Supporting member campaigns and user groups who are explicitly working to place mental health within the context of wider social justice and human rights. For example, hosting user-led networks such as North East Together (Welfare Rights Action Group), Real Insight, Kindred Minds (BME Manifesto project).
- Publishing 91 member blogs, covering personal accounts of marginalisation and distress, commentary on policy and sharing of ideas and work.
- Submitting a report to Philip Alston about devastating experiences of austerity for people with lived experience.
- Presenting Members' Manifesto webinar for the Association of Mental Health Providers.
- Attending and contributing to the 'Scrap Universal Credit' event organised at Parliament by the TUC Disabled Workers' Committee, Unite the Union and Disabled People Against Cuts (DPAC).

### NSUN will:

- Continue to join forces with other organisations and user-led groups across the country and outside the area of mental health that are working to oppose cuts to public funding.
- Gather relevant, up to date information about people's experiences and share our knowledge and insights with other organisations and politicians working to oppose cuts.
- Ensure that the weekly bulletin includes updates, developments and opportunities across the country for people to support projects, campaigns etc. to address the harm being caused as a result of cuts.
- Continue to support individual member campaigns and user groups who are working to oppose cuts.
- Promote the importance and right to access different types of support such as Personal Budgets, Access to Work and Disabled Students' Allowances.
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## 2. Challenge the abuse and coercion that continues under mental health legislation and work to ensure that people understand and can enforce their rights under the UNCRPD.

### What does this mean and why is it important?

Being on the receiving end of mental health services continues to be a damaging and traumatising experience for many people. All too frequently it can lead to discrimination, isolation and loss of power. **Coercion** and restraint practices have been consistently shown to cause harm.<sup>21</sup>

We believe in a **rights-based approach** that fully respects and upholds our human rights. Therefore, throughout the period of review for the Mental Health Act we have been campaigning with a wide range of other user-led groups, people with lived experience and allies who have the same concerns for legal reform that would ensure compliance with the full human rights set out in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).<sup>22</sup> We have used the UNCRPD's **social model** approach, the importance of looking at what has happened to someone, rather than giving dominance to a **biomedical model**, including the Convention's emphasis on bringing substitute decision-making, detention in psychiatric institutions and forced treatment to an end.

But we also know that this is a complex issue, that calling for a complete end to all detention can be emotive for some people and that there are some mixed views. We represent a membership that is broad and diverse, including members who feel that, as a last resort, detention is sometimes necessary in a period of crisis.

The position set out in the Hearing Voices, Mental Health Act Alternative Review recognises:

*"the need for short term detention (under 72 hours) in extreme circumstances. This should be understood as a grave decision of the last resort, having exhausted all other options and should take place with the most stringent of safeguards. We call for an end to longer-term detention under the Mental Health Act in order to administer treatment, including forced medication. This can only take place alongside the implementation of a meaningful range of well-funded alternative mental health and social support".<sup>23</sup>*

NSUN's campaign has gone further because of the wide range of user-led groups and people with lived experience who have asked for it to do so.

Violent and traumatic detentions and enforced treatment that denies people their human rights are always unacceptable. However, whilst there is still a legally permitted use of detention, clinicians should act as compassionately and offer as much choice, dignity and respect as they can under current mental health law.

Settings and environments should genuinely feel like places of safety and

<sup>21</sup> Rose, D., E. Perry, S. Rae, and N. Good, 2017. Service user perspectives on coercion and restraint in mental health, *BJPsych International* 14(3): 59–61.

<sup>22</sup> [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GBR/CO/1&Lang=En](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GBR/CO/1&Lang=En)

<sup>23</sup> Hart, A. and R. Waddingham, 2018. The Mental Health Act: An Alternative Review. Hearing Voices Network. p.3.

sanctuary and should always take people's individual needs into account. However, with notable exceptions (for example, user-led services such as the Leeds Crisis House, or the Suicide Crisis Centre in Gloucestershire), the reality continues to be one where alternatives to hospital are not available, where there have been severe cuts to advocacy services, where illegal detentions take place in A&E departments and where unacceptable blanket policies regarding the searching of bags and possessions continue unchecked.<sup>24</sup> NSUN members have also reported experiencing verbal and physical attacks and sexual abuse.<sup>25</sup> Commissioning of alternatives, as well as an immediate end to these practices, needs to happen as a matter of urgency.

Whilst continuing to campaign at policy level, our work also needs to be rooted in the day-to-day reality of people's experiences to help them understand the rights they have and how to enforce them within mental health settings.

### We have been doing this this by:

- Lobbying for wider engagement of people affected by mental health legislation
- Securing a place on the Independent Review of the Mental Health Act Advisory Panel and representing campaign points from NSUN and the range of people/organisations who have signed up to these, including people with learning difficulties
- Contributing relevant campaign points to the 'Addressing rising rates of detention' Mental Health Review Topic Group
- Keeping members informed about the progress and outcomes of the review
- Providing templates to lobby local MPs for a Mental Health Act that is fully compliant with the human rights set out in the UNCRPD
- Co-ordinating meetings of user-led groups to make representations to the Independent Review of the Mental Health Act Advisory Group
- Sending letters of concern about the Mental Health Act Review to leaders of the main political parties, All Party Parliamentary Groups and Parliament's Joint Committee on Human Rights
- Talking directly with some ministers/shadow ministers and with representatives from the Office for Disability Issues
- Liaising with trade unions about human rights concerns which they would also support
- Providing input to the development of indicators for the first set of Human Rights draft indicators relating to the Convention on the Rights of Persons with Disabilities (CRPD)
- Supporting the Parliamentary launch of the Deaf and Disabled People's report about UK progress with the UNCRPD
- Challenging inhumane and coercive mental health law practices through a written submission sent to the Committee for the United Nations Convention Against Torture (UNCAT) and through a verbal submission made during the subsequent examination of the UK government in Geneva
- Commenting on difficulties with the Equality and Human Rights Council (EHRC) Human rights framework for restraint: principles for the lawful use of physical, chemical, mechanical and coercive restrictive interventions.

<sup>24</sup> <https://www.hsj.co.uk/policy-and-regulation/mental-health-matters-punitive-practices-/7024848.article>

<sup>25</sup> See for example, Rachel Rowan Olive (2018) <https://www.mentalhealthtoday.co.uk/blog/awareness/the-complaints-i-never-made> Mental Health Today.

### NSUN will:

- Continue to join forces with other organisations and user-led groups across the country to provide for recommendations and campaign for legal change to ensure treatment services are fully compliant with human rights set out in the UNCRPD.
- Continue to attend the Mental Health Act Review Advisory Group.
- Plan further campaign action
- Emphasise the need to put the sorts of resources in place which make it possible for detention not to be used
- Keep members informed of progress and developments.
- Facilitate collective responses and meetings.
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## 3. Actively promote the need to work with us in decisions about strategy, commissioning and how services are provided, as well as the need for services to be user-led.

The involvement of people who use mental health services is an important emphasis in the UNCRPD. Co-production has been legislated for by the UK government, but is still not practised as the norm.<sup>26</sup> With over 4,000 members, NSUN is able to assemble a national picture of mental health services and support. Across the country our members report that although the language of 'co-production' is now commonplace, the reality is very different and that user-led services and initiatives continue to be small in number.

All too often the 'involvement' and 'co-production' activities of mental health services continue to be experienced as tokenistic tick box consultation exercises. Commenting on decisions made by others is not co-production. Making decisions is.

Genuine co-production will involve commissioners and clinicians learning how to share their power with service users and survivors; listening to us, respecting us and treating us as equals. To be effective, co-production in mental health services must account for the unique and entrenched power imbalances in the system.

A major concern, too, is that resource shortfalls have led to the closure of an increasing number of user-led groups.

Drawing on a growing body of user-led and co-produced research and guidance on effective involvement and co-production,<sup>28 29 30</sup> we believe that:

- Effective and meaningful involvement in individual care and treatment lead to self-esteem, improve individual outcomes and increase people's satisfaction with services
- Genuine partnerships between mental health services, professionals,

<sup>26</sup> Department of Health, 2013. Patients First and Foremost: initial Government Response to the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, London: Department of Health. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/170701/Patients\\_First\\_and\\_Foremost.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/170701/Patients_First_and_Foremost.pdf)

<sup>27</sup> Carr, S., 2016. Position Paper: Are mainstream mental health services ready to progress transformative co-production? Bath: NDTi

<sup>28</sup> Crepez-Keay, D., 2014. Effective Mental Health Service User Involvement: establishing a consensus on indicators of effective involvement in mental health services, PhD thesis, Middlesex University. [http://eprints.mdx.ac.uk/13932/1/DCrepaz-Keay\\_thesis.pdf](http://eprints.mdx.ac.uk/13932/1/DCrepaz-Keay_thesis.pdf)

<sup>29</sup> Faulkner, A., 2015. Influence for Improvement – the 4Pi Standards for Involvement, London: National Involvement Partnership/National Survivor User Network. <http://www.nsun.org.uk/assets/downloadableFiles/NIPStandardsforInvolvement4PiFINAL20142.pdf>

<sup>30</sup> National Development Team for Inclusion (NDTi), 2016. Progressing transformative co-production in mental health, Bath: NDTi [http://www.ndti.org.uk/uploads/les/MH\\_Coproduction\\_guide.pdf](http://www.ndti.org.uk/uploads/les/MH_Coproduction_guide.pdf)

- ▶ people using services and their carers lead to enhanced quality of care, and a reduction in compulsory admissions
- User-led and user-controlled services are valuable and should be commissioned to give people more choice and control over how their support needs are met.
- The importance of our input into decisions about strategy, commissioning and service provision should be recognised by payment at equitable rates

Meaningful and inclusive involvement starts with a commitment to shared principles and values. The 4Pi National Involvement Standards (developed in order to strengthen the user and carer voice in the planning, delivery and evaluation of services) states that involvement benefits from the following shared principles and values.

### A commitment to:

- Improve services and improve the wellbeing of all individuals
- Acknowledge the **power differentials** that exist between people, and commit to minimise them wherever possible
- Listen to people with respect and openness
- Change in response to the views and people with lived experience of distress
- Support race equality and challenge discriminatory practices
- An open-minded approach towards cultural differences and diversity in ways of working
- Inclusivity, equality of opportunity and fairness
- Clarity and transparency
- Sensitivity about language and actions... an understanding that there are different ways of expressing and doing things.<sup>31</sup>

### We have been doing this by:

- Continued promotion of the 4Pi National Involvement Standards and of signing-up to them
- Producing the 4Pi brochure
- 4Pi training delivered to Rethink, South London and Maudsley NHS Foundation Trust and Lincolnshire NHS Partnership Trust
- Partnership working with other user-led organisations and groups, such as Shaping Our Lives, Inclusion London, HEAR Network, Wish.
- Delivering peer mentoring training
- Facilitating quarterly national service user involvement worker meetings
- Hosting user-led initiatives: Real Insight, Kindred Minds, BME Manifesto, North East Together.
- Tracking the use and impact of the 4Pi standards through the production of the Reality and Impact project report.
- Working with other user-led groups to highlight the vital role of user-led groups and the need for a major increase in funding for them.
- Joining other user-led groups to draw current shortfalls in co-production and in support for user-led groups to the government's attention.

### NSUN will:

- Ensure that there is an equal and strong user voice at an individual, community, organisational and strategic level, in all services and settings

- through the promotion and implementation of involvement standards.
- Continue to encourage services and organisations to endorse the 4Pi National Involvement Standards and commit to these principles and values.
- Build on the knowledge generated through the 4Pi Reality and Impact project report by continuing to track the use and impact of the 4Pi standards (eg. developing case studies and sharing how the standards have been used by different organisations and in different settings).
- Take forward the recommendations of the 4Pi Reality and Impact project report (including the development of additional training materials and packages that can be accessed to enable everybody to have the best possible experience of involving people and being involved).
- Continue pressing for a major increase in funding for user-led groups and initiatives.
- Continue to join other user-led groups in lobbying the government about the need to make co-production a reality and to support user-led initiatives.
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## 4. Challenge personal, institutional and structural inequalities, injustices, disadvantages and discrimination for everyone with experience of mental distress/trauma

### What does this mean and why is it important?

Achieving equality can be extremely difficult for some communities, including people:

- From black, asian, minority ethnic and refugee (BAMER) communities;
- Who identify as lesbian, gay, bisexual, transgender, intersex, or queer/questioning (LGBTIQ+);
- Who are in older or younger age groups;
- Who are women;
- With physical disabilities and sensory impairments, or are Deaf people;
- People with learning difficulties and/or autism;
- With long term/physical health conditions;
- Who belong to disadvantaged socio-economic groups;
- Who have experienced homelessness
- Who have drug and/or alcohol addictions.

If you identify with more than one of these groups, it is often even more difficult to find and receive the right kind of support from mainstream services.

### Why is it so difficult?

The Equality Act (2010) makes it unlawful to discriminate against people with

<sup>31</sup> National Survivor User Network (2014) 4Pi National Involvement Standards: Executive Summary. <https://www.nsun.org.uk/Handlers/Download.ashx?IDMF=e1c3ca4-c32e-47ff-8795-c45f523458c1>



► a ‘protected characteristic’ (age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; sexual orientation). However, the Act has shortcomings itself, for example the protected characteristics do not cover people from disadvantaged socio-economic groups. The group, Health Inclusion is currently exploring systemic issues in relation to health inequalities and how the most excluded groups and populations who are not protected by the Equalities Act can have equal access to health services.

Discrimination and serious, damaging inequalities still exist within our society and its institutions.<sup>32,33</sup> This includes mainstream mental health services. For example, a high percentage of BAME people experience discrimination from individuals working in the health system.<sup>34</sup> Their own understandings of and approaches to their mental health distress and/or diagnosis are also less likely to be listened to and included in recovery and care plans.<sup>35</sup>

At policy level, following the death of David Bennett in 1998, the Delivering Race Equality programme was set up to address institutional racism within the NHS.<sup>36</sup> Despite some drawbacks, progress was made during the lifetime of the programme. But more recently, race equality has fallen off the agenda and much of the progress in infrastructure and policy with regard to race equality is now under threat.<sup>37</sup>

Institutional discrimination also exists for LGBTIQ+ people.<sup>38</sup> LGBTIQ+ people are more likely to develop mental health distress and are at a higher risk of suicide and self-harm.<sup>39</sup> There continue to be concerns about ‘reparative’ or ‘conversion’ therapy (which aims to change sexual orientation or reduce attraction to others of the same sex) resulting in a government commitment to ban this practice as part of its equality plan.<sup>40</sup>

Policy efforts to address discrimination and sexual violence against women in mental health services and inequality relating to age have also stalled over the past five to ten years.<sup>41</sup>

Discrimination, oppression and inequality faced by people with mental health diagnoses needs to be challenged and particular work needs to be done to address specific issues for people and communities who face discrimination in more than one way.<sup>42,43</sup> This is sometimes referred to as ‘**intersectionality**’.<sup>44</sup>

Mental health services and other services needed by people with lived experience must be held to account. We will do this by working with other groups who are campaigning in these areas and using rights-based work to challenge inequalities and discrimination.

## We are doing this by:

- Supporting publishing the BME service users’ manifesto ‘A Call for Social Justice’.
- Establishing the ‘Reigniting the Space’ national forum to facilitate networking and collaboration between racialised groups to sustain a political voice.
- Challenging the lack of diverse voices included in national surveys, initiatives and on policy boards.
- Supporting individual member campaigns (eg. young people’s experiences of street violence including racial/religious abuse or attacks).

32 <https://www.stonewall.org.uk/lgbt-britain-health>

33 <https://www.theguardian.com/world/2017/may/30/why-im-no-longer-talking-to-white-people-about-race>

34 Rehman, H. and D. Owen, 2013. Mental Health Survey of Ethnic Minorities, Ethnos Research and Consultancy. [https://www.time-to-change.org.uk/sites/default/files/TTC\\_Final%20Report\\_ETHNOS\\_summary\\_1.pdf](https://www.time-to-change.org.uk/sites/default/files/TTC_Final%20Report_ETHNOS_summary_1.pdf)

35 Gould, D., 2012. Service users’ experiences of recovery under the 2008 Care Programme Approach. [https://www.mentalhealth.org.uk/sites/default/files/CPA\\_research\\_study.pdf](https://www.mentalhealth.org.uk/sites/default/files/CPA_research_study.pdf)

36 Wilson, M., Mental Health Equalities Programme, National Mental Health Development Unit, 2010. Race Equality Action Plan: a five year review [http://data.parliament.uk/DepositedPapers/Files/DEP2014-0975/PQ202552\\_PQ202500\\_-\\_Report.pdf](http://data.parliament.uk/DepositedPapers/Files/DEP2014-0975/PQ202552_PQ202500_-_Report.pdf)

37 Kalathil, J., 2016. Race hitting the headlines? NSUN Newsletter, Issue 10 – Spring 2016

38 Somerville, C., 2015. Unhealthy Attitudes: The treatment of LGBT people in health and social care services. London: Stonewall. <https://www.stonewall.org.uk/resources/unhealthy-attitudes-2015>

39 Nodin, N., E. Peel, A. Tyler and I. Rivers, 2015. LGB&T Mental Health – Risk and Resilience Explored. London: PACE – Project for Advocacy Counselling and Education. [http://www.queerfutures.co.uk/wp-content/uploads/2015/04/RARE\\_Research\\_Report\\_PACE\\_2015.pdf](http://www.queerfutures.co.uk/wp-content/uploads/2015/04/RARE_Research_Report_PACE_2015.pdf)

40 <https://www.bbc.co.uk/news/uk-44686374>

41 Agenda, 2016. Women’s needs in mental health services: A Response to an FOI Request London: Agenda.

42 Kalathil, J., 2013. Dancing to our own tunes: reprint of the 2008 report with a review of work undertaken to take the recommendations forward, London: National Survivor User Network. [https://www.academia.edu/3297509/Dancing\\_to\\_our\\_own\\_tunes\\_Reassessing\\_black\\_and\\_minority\\_ethnic\\_mental\\_health\\_service\\_user\\_involvement](https://www.academia.edu/3297509/Dancing_to_our_own_tunes_Reassessing_black_and_minority_ethnic_mental_health_service_user_involvement)

43 See for example, combined age and gender discrimination cases that have been unsuccessful (Miriam O’Reilly vs. BBC) <http://www.stammeringlaw.org.uk/discrimination/multiple.htm>

44 Crenshaw, K., 1991. Mapping the Margins: Intersectionality, Identity Politics and Violence Against Women of Color. *Stanford Law Review*. 43:6, pp. 1241-1299

- Taking forward the recommendations from Ethnic Inequalities in Mental Health
- Working with local and national groups to ensure the voices of socially deprived and marginalised communities are included by projects, surveys and research projects, such as the Independent Review of the Mental Health Act, Healthy Lives London, Reigniting the Space, Healthwatch, and the CQC.

## NSUN will:

- Commit resources and develop work that see all people who face more than one type of disadvantage taking the lead and participating in meaningful involvement.
- Aim to work directly with BAME and LGBTIQ+ groups to ensure that the membership truly represents the diversity of people with experience of mental distress.
- Ensure messages and presentation of information express the diversity of views and experiences of our members.
- Facilitate and strengthen communications between members and communities.
- Support user and community-led groups and grassroots activities in local areas.
- Link work to broader rights-based projects that address social inequalities and challenge violence and discrimination.
- Embed a rights-based approach in our work through leadership programmes, the development of resources and signposting to other services and organisations.
- 

## 5. Promote informed choice so that people are in a position to understand their difficulties in whatever way they choose and to access the support that they find best.

### What does this mean and why is it important?

We believe that people experiencing mental or emotional distress should have real choices and control over their own lives. Disability rights organisations call this ‘independent living’<sup>45</sup> Independent living is not just about being able to live in your own home (although it can mean that for some people).<sup>46</sup> Neither is it about doing things for yourself without support.<sup>47</sup> Instead it means that people are not institutionalised, but are able to choose where they live, how they define themselves and what assistance they need and can live as equal citizens in a society that is accessible and inclusive,

45 Reclaiming our Futures Alliance. 2019. Independent Living for the Future: Our vision for a national independent living support system. (London: Reclaiming our Futures Alliance).

46 Prime Minister’s Strategy Unit, 2005. Improving the life chances of disabled people. (Prime Minister’s Strategy Unit with Department for Work and Pensions, Department for Health, Department for Education and Skills, Office of the Deputy Prime Minister).

47 Reclaiming our Futures Alliance. 2019. Independent Living for the Future: Our vision for a national independent living support system. (Reclaiming our Futures Alliance, 2019).

and where services are available and accessible to everyone. The idea of independent living has developed from the **Social Model of Disability** which argues that disability is caused by the way society is organised and the barriers it presents, not by someone's difference or impairment.

The right to independent living and being included in the community is set out in Article 19 of the UN Convention on the Rights of People with Disabilities (UNCRPD)<sup>48</sup> But the recent 'Independent Living for the Future' report states that in the UK at government and policy level the language of independent living is being used, but at the same time essential social care support is being removed, which shows that there continues to be a lack of understanding about what independent living actually is.<sup>49</sup>

For people experiencing mental or emotional distress 'independent living' includes: receiving accessible and timely information to help make informed decisions; being offered a range of available support options (as well as a choice of service provider in parity with physical health) so they can choose they find best; an end to substitute decision-making and access to supported decision-making; having the freedom to understand their experiences of distress in whatever way they choose. This might mean accepting or rejecting diagnoses, choosing to take medication if that is helpful for them and/or accessing alternative forms of support including long term talking therapies, holistic alternatives, peer support etc.

### We have promoted a right to informed choice by:

- Supporting members' campaigns in this area, for example: 'Holistic Wellbeing', and 'Prescribed Medication - the long-term effects'.
- Membership of the All-Party Parliamentary Group for Prescribed Drug Dependence
- Hosting the launch event and panel discussion of the report 'From Mental Illness to a Social Model of Madness and Distress' with Shaping Our Lives (NSUN AGM Birmingham, 2016).
- Contributing to annual material about independent living in the UK which the user-led UNCRPD Monitoring Coalition currently submits to the Convention's Committee.
- Participating in and contributing to relevant events about independent living, for example the designing of a National Independent Living Service and this year's Freedom Drive by the European Network on Independent Living.

### NSUN will:

- Work with other disability rights organisations to support the universal right to independent living.
- Signpost and research options on behalf of people when they are finding this difficult to do themselves. NSUN does not provide formal advocacy or advice but does provide mutual support and understanding and is committed to dedicating time to the immediate needs of members.
- Continue to build a platform for the service user voice and collective knowledge
- Build capacity in the movement at local and regional levels, developing infrastructure and resources for local groups and supporting their activities and campaigns
- Facilitate local networking and support the development of strong member-led hubs. ●

48 UNCRPD, 2006. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

49 Reclaiming our Futures Alliance. 2019. Independent Living for the Future: Our vision for a national independent living support system. (Reclaiming our Futures Alliance, 2019).

## 6. Promote the validity and vital role of survivor knowledge and research

### What does this mean and why is it important?

Survivor/service user research is carried out by people who have experienced mental or emotional distress including those who have used mental health services.<sup>50 51</sup> It is different from traditional Patient and Public Involvement (PPI) in research because survivors and service users have control over the research process.<sup>52</sup>

This type of research has grown from the political roots of survivor activism that challenges the psychiatric system, biomedical 'illness' models and the research associated with them. Survivor/service user researchers work together to develop different forms of knowledge and different ways of doing research in mental health.

Although a growing number of survivors/service users are involved in mental health research, very often this involvement is limited to advisory groups or consultancy roles.<sup>53 54</sup> Many survivors/service users who are new to research are not supported or enabled to develop their research skills and many of those who have research training and experience are not receiving proper recognition for their skills. Survivors/service users with research qualifications can be excluded from research projects and this prevents them from contributing their skills and knowledge.<sup>55</sup> This reinforces the disempowering idea that you cannot be both a survivor/service user and a qualified researcher. A key, additional issue which needs addressing is the under-representation of survivor researchers from marginalised communities in research studies and in user-led studies.

Survivor-led research is an independent and important discipline in its own right. It is vital that survivor and service user researchers are not ignored or overlooked within research processes, but are enabled to produce and lead research.<sup>56</sup>

### We are promoting survivor knowledge by:

- Addressing issues arising from the co-option of survivor/service user research into Patient and Public Involvement (PPI) initiatives by the NHS, universities and the mental health charities.
- Addressing the broader social issues of marginalisation, oppression, inequality and poverty, and questioning the relationship between deepening inequalities in research.
- Critically examining survivor/service user research and knowledge itself, particularly when much of the (known) history of the movement is white and has made assumptions that everyone is heterosexual.
- Committing to working with groups from a diverse range of different communities, identities and backgrounds.

### NSUN will:

- Sustain and develop the Survivor Researcher Network (SRN) so that it can provide survivor/service user researchers with a forum for networking, sharing information and supporting each other by:
- Challenge the hierarchy of evidence and promote the validity of experiential

50 Faulkner, A., 2004. The ethics of survivor research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors. Policy Press.

51 We also acknowledge that many people with lived experience of mental distress have or have had a caring role.

52 See the Survivor Researcher Network Manifesto for further details. Ormerod, E. et al., 2018. Survivor Researcher Network Manifesto London: NSUN.

53 Patterson, S., Trite, J. and Weaver, T., 2014. Activity and views of service users involved in mental health research: UK survey. The British Journal of Psychiatry, 205(1), pp.68- 75.

54 Rose, D., Carr, S. and Beresford, P., 2018. Widening cross-disciplinary research for mental health: what is missing from the Research Councils UK mental health agenda?, Disability & Society, 33:3, 476-481.

55 Open Letter to Lancet Psychiatry from Building User/ Survivor Research Capacity & Leadership (2018) <https://www.mentalhealthexcellence.org/open-letter-to-lancet-psychiatry-from-building-user-survivor-research-capacity-leadership/>

56 Rose, D., Carr, S. and Beresford, P., 2018. Widening cross-disciplinary research for mental health: what is missing from the Research Councils UK mental health agenda?, Disability & Society, 33:3, 476-481.



- ▶ and survivor knowledge(s), as well as participatory and emancipatory research methods
- Promote authentic and influential survivor and service user involvement and leadership in research
- Continue to seek partnerships with organisations and institutions to increase opportunities for SRN members and ensure genuine, meaningful co-production and involvement in research.
- Campaign for a major increase in the funding of survivor-led research and for equitable pay for survivor/service user researchers who join research teams.
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One of the goals of our manifesto is not only to directly set out our aims and how we intend to achieve them, but also to communicate these aims in a way that is clear and easy to understand. This glossary contains terms that may cause confusion, be unfamiliar or that need further clarification. We also acknowledge that there are other terms not mentioned here that it may be helpful to add in the future.

### **Service user, survivor, person with lived experience**

The most important thing to clarify is our use of ‘service user’, ‘survivor’ and ‘people with lived experience of mental distress’. Many of our members describe themselves as ‘survivors’, not only of the effects of mental distress but also of the psychiatric system. However, the most recent term used by policy makers and practitioners to describe those on the receiving end of mental health service is ‘service user’. While we use both terms in this document, we also refer to ‘people with lived experience of mental distress’. In a recent NSUN poll of preferred terms, this was the term that members identified with most strongly.

### **Austerity**

Austerity refers to measures designed to reduce government budget deficits through spending cuts and tax increases. In recent years, austerity measures were undertaken by the Coalition government formed in 2010, a programme that has included harsh cuts to the welfare state and a reduction in funding for essential public services, including mental health and social care services, education, housing and more. In 2018, the UN poverty envoy said that the UK government had inflicted “great misery” on its citizens through austerity measures: he also noted that around 14 million people live in poverty and 1.5 million are destitute. And in early 2019, the Special rapporteur on health for the UN stated that stopping austerity measures should be the government’s primary objective when it came to tackling mental distress.

### **Biomedical model**

The biomedical model of illness focuses on purely biological factors, ignoring social, psychological and environmental factors. When it comes to mental distress, the biomedical model treats mental illness as a ‘disease’, with research focusing on the chemical and medical underpinnings of certain diagnoses, and treatment focusing not on social or psychological factors but primarily on medication-based approaches.

### **Co-production**

Co-production is intended to put survivors/service users at the heart of service development and delivery

– essentially meaning that those with relevant lived experience take part in every step along the way of a development and delivery journey. In theory, this also means everybody involved – service users, mental health professionals, policymakers and more – should be thinking about the relative power they have within this hierarchy.

### **Coercion**

Coercive treatment can include compulsory admission of patients, or coercive or compulsory treatment measures such as over-medication, restraint, or seclusion.

### **Holistic therapies**

Holistic therapy is a form of therapy that considers the whole person – body, mind, emotions, spirituality, social factors and more are all considered.

### **Informed choice**

Informed choice is when someone is given numerous options to choose from in a healthcare setting – from diagnostic tests to treatments – as well as knowing the full details of such options, including benefits, risks and outcome.

### **Intersectionality**

The term ‘intersectionality’ was first used by black feminist academic, lawyer and civil rights activist Kimberlé Crenshaw in the late 1980s. She believed that feminism and anti-racist movements were both excluding black women because they sat in the middle of two overlapping discriminations – misogyny and racism. In other words, intersectionality refers to the cumulative impact that multiple forms of discrimination have on marginalised groups – this can include racism, classism, sexism, ableism and more.

### **Power differentials**

A power differential refers to the difference between two people in terms of status and authority. In mental health services, there could be a power differential between a service user, who has very little power, status or authority within the relationship, and a professional, who has more.

### **Rights-based approach**

A rights-based approach focuses on ensuring human rights are put at the centre of policy and delivery or services. This means service users should be involved in decisions that affect their human rights; that there should be careful monitoring of how human rights are being impacted and clear steps to follow when this is not happening; that practices should be anti-discriminatory; and that everybody should understand their rights.

# Glossary of terms

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## ▶ **Sanctions**

Sanctions happen when someone claiming benefits 'fails to comply' with certain rules – for example attendance at the Job Centre – and is docked their entitled pay, or loses it entirely, as punishment. One study found that sanctions were not only cruel but completely ineffective at getting people into work, and were "more likely to reduce those affected to poverty, ill health or crime".

## **Self advocacy**

Self advocacy refers to someone's ability to stand up for themselves, ask for what they need and make choices that impact their life. This, as with having informed choice, also includes understanding your rights in full. These skills can be useful in a number of situations: when you are being offered treatment or diagnosis, when you are reviewing or creating a care plan with a professional, or when you need to make a complaint about a service, experience or practitioner.

## **Social discrimination**

Social discrimination refers to sustained inequality between people based on illness, disability, gender, race, sexual orientation or any other factor. For many people, discrimination is experienced in various overlapping areas – see the entry for intersectionality.

## **Social model of disability**

The social model of disability argues that disability is caused by the way society is organised and the barriers it presents, not by someone's difference or impairment. This can be a physical barrier – non-accessible toilets or a building entrance without a ramp. Or it can be a problem with people's attitudes – assuming someone disabled is incapable of doing certain things or should have to change the way they work or live to adapt to an inaccessible world.



**It's time for service users and survivors to lead the agenda, rather than responding to it.**

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