



Manifesto 2017

Our voice Our vision Our values



Members' manifesto for mental health

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The National Survivor User Network (NSUN) is an independent charity led by survivors and service users that connects people with lived experience of mental distress to give us a stronger voice in shaping policy and services.¹

Our Members' Manifesto is an evolving document. Using feedback from our annual survey (2015) and Top 10 Issues identified by members, the Members' Manifesto 2017 updates our previous work and draws together our aspirations, intentions and key demands with regard to mental health policy and practice. It is not exhaustive of all issues, concerns and communities but represents the priorities expressed by our members.

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

Our mission is to become the national voice of all service users in England to communicate their needs and to challenge government and mental health care providers to drive the service towards a better future.

Why is this manifesto different?

This document outlines the key issues in mental health from the perspective of people with lived experience. That's 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 and policy makers and
- c) help change take place in our society.

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Members' manifesto for mental health

We aim to:

1. Address the injustice and harm that have been caused by cuts to public funding and changes to the benefits system
2. Make the policy of 'getting the right support, at the right time, in the right place, from the right person' a reality
3. Pressure mental health services to make the principle of 'nothing about us without us' a reality at all levels, through meaningful involvement in decisions about our own individual care and genuine co-production to develop services
4. Work together with people from socially deprived and marginalised communities to determine their support and develop alternatives
5. Challenge institutionalised discrimination and put equality back on the agenda for mainstream mental health services
6. Call for a reform of the Mental Health Act 2007 to make it fully compliant with human rights legislation and ensure that people are not harmed or abused
7. Reflect the social model of disability and promote informed choice and alternatives to medication
8. Reclaim, challenge and revive survivor knowledge and research

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Introduction

The Mental Health Taskforce report was published in February 2016.² It summarises the current state of NHS mental health care and makes recommendations using the issues raised as the basis for a five-year strategy.

The report highlights that:

- Only 14% of adults in crisis felt they were provided with the right response (Care Quality Commission findings)
- Men of African and Caribbean heritage are up to 6.6 times more likely to be admitted as inpatients or detained under the Mental Health Act
- People with long term mental health problems are at risk of dying on average 15 to 20 years earlier than other people.³

NSUN welcomes the fact that the report draws attention to just how many mental health needs are currently being unmet in England. But this is only a strategy for the NHS. It does not address:

- the profound lack of spending on social care
- the continuing effects of local authority spending cuts, including on grassroots, independent user-led and community support organisations
- the ways welfare reforms have disproportionately affected those with long-term mental health needs.

Moreover, while the Taskforce report discusses the problems and concerns of people from black, asian and minority ethnic (BAME) communities, there are very few firm recommendations for addressing race equality or tackling the systemic and attitudinal discrimination that also effects LGBTIQ+ (lesbian, gay, bisexual, transgender, intersex, queer plus) people, women, older people and those from marginalised communities. The proposed champion for equalities and health inequalities must urgently address this situation for these different groups in mental health.

We know that funding cuts are continuing to have a devastating affect on many, but are disproportionately affecting people who are already living on a low income, disabled people and BAME service users who are already more likely to be living in poverty than most white British families.⁴ Research shows that reduction in public spending has left many people from the LGBTIQ+ community without adequate specialist or community support.⁵

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1. ADDRESS THE INJUSTICE AND HARM THAT HAVE BEEN CAUSED BY CUTS TO PUBLIC FUNDING AND CHANGES TO THE BENEFITS SYSTEM

Since 2010, 'austerity' has been the UK government's dominant economic policy. This has led to severe cuts in public spending (especially welfare benefits and local authority funding). These cuts are leading to increasing inequality and poverty.

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. This has severely affected the mental and physical wellbeing of people, some of whom have reportedly attempted or completed suicide after benefits have been withheld.⁶

The political ideology responsible for this situation is called 'neoliberalism'.⁷ Neoliberalism means that the state withdraws from collective welfare and social provision. The role of the state sees itself as being limited to the creation of frameworks that only support free markets. Within this system, people who are perceived as wealthy or 'hard-working' are seen as virtuous and deserve their success. People who do not succeed in the terms of this ideology are personally blamed for their perceived 'failure'. There is no recognition of the effects of personal or community history or the wider social systems of inequality.

Clinical psychology and therapy have now been incorporated into government action and psychological 'assessments' and 'interventions' are being directed against people on benefits with disabilities and health problems.⁸ This strategy is being used in order to explain unemployment by locating the problem with the individual (ie. people who are unemployed are perceived as 'psychologically resistant' to work) and introducing compulsory activities aimed at changing beliefs so that individuals have the 'right' attitude for work.

The personal 'recovery model' has been colonised by psychiatry, mental health services, commissioners and policy makers, with negative consequences for service users and survivors.⁹ Yet personal recovery is about recovering a life and identity after a mental health crisis and psychiatric treatment. It has implications far beyond services.¹⁰

(Deegan, 1987).

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".¹¹ Welfare benefit reforms are destroying many people's chances of living their lives.

nsun will:

- **Work to challenge current political ideology and its associated practices in health, social care and welfare that are causing harm to so many people in society**
- **Support member campaigns and user groups who are explicitly working to place mental health within the context of wider social justice and human rights.**
- **Promote the importance and right to access different types of support such as Personal Budgets, Access to Work and Disabled Students' Allowances**

2. MAKE THE POLICY OF 'GETTING THE RIGHT SUPPORT, AT THE RIGHT TIME, IN THE RIGHT PLACE, FROM THE RIGHT PERSON' A REALITY

The National Institute for Health and Care Excellence (NICE quality Standard 14) sets out guidelines for 'service user experiences' in adult mental health.¹² It details the importance of timely appointments, empathic staff, shared decision-making, clear information and support options.¹³ But we know this is not the experience of many people who use mental health services. For example, the CQC reports that the safety of patients in NHS trust is a key area of concern and that overall ratings indicate that "care for people experiencing mental health problems is not good enough and needs to be improved".¹⁴

Across the country, our members continue to report negative experiences of a mental health system where people face an ongoing battle to exert control, and to know and exercise their basic rights.

Our members tell us they want:

- Access to the right kind of support – whether that is talking therapy, medication, peer support or a combination of these
- Inpatient settings that are safe therapeutic environments where human rights are not breached by coercive or abusive practices such as chemical or physical restraint
- Improved access to services and support when we need them - without "having to jump through endless hoops to qualify", including 24/7 crisis services
- Improved community mental health and early intervention services for young people and adults
- Access to and clear information about and support to use personal budgets and direct payments
- Consistent mental health services and peer support that share and replicate good practice across the country
- Appropriate accommodation for everyone detained under Section 136 of the Mental Health Act so that detention in a police cell is not the only option when providing a place of safety
- Integrated health and social services, to provide necessary housing, physical health services and other support, particularly when leaving inpatient care.

nsun will:

- **Continue to work with a wide range of professionals including frontline staff, managers, clinicians, social workers, forensic services, service providers, commissioners, researchers, regulators, and advocacy advisory groups, to influence improvements in the quality and appropriateness of treatment and mental health care.**
- **Put members at the forefront of campaigning and work with members to support and develop their own campaigns (for example, with regard to abusive practices of forced medication, restraint and seclusion, and stripping).**
- **Lobby on behalf of people with lived experience with the aim of challenging and changing current mental health policy and practice.**
- **Facilitate collective responses that are direct, independent and communicated in an unbiased and unfiltered way**
- **Continue to collate people's experiences of restraint and inform people of their rights with regard to acceptable practices.**

3. PRESSURE MENTAL HEALTH SERVICES TO MAKE THE PRINCIPLE OF "NOTHING ABOUT US WITHOUT US" A REALITY AT ALL LEVELS

The involvement of people who use mental health services has been legislated for, but is still not practised as the norm.¹⁵ 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 rhetoric of 'involvement' and 'co-production' is now commonplace, the reality is very different.

All too often the 'involvement' and 'co-production' activities of mental health services continue to be experienced as 'tick box' consultation exercises by people with lived experience. Commenting on decisions made by others is not co-production, making the 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 must account for the unique and entrenched power imbalances in the system.¹⁶

Drawing on a growing body of user-led and co-produced research and guidance on effective involvement and co-production.^{17 18 19}, we believe that:

- Effective and meaningful involvement in individual care and treatment can raise self-esteem, improve individual outcomes and increase people's satisfaction with services
- Genuine partnerships between mental health services, professionals, people using services and their carers can lead to enhanced quality of care, and a reduction in compulsory admissions
- User-led and user-controlled services should be commissioned to give people more choice and control over how their support needs are met.

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.²⁰

 **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.**

4. WORK TOGETHER WITH PEOPLE FROM SOCIALLY DEPRIVED AND MARGINALISED COMMUNITIES TO DETERMINE THEIR SUPPORT AND DEVELOP ALTERNATIVES

The needs of people with lived experience from marginalised communities continue to be overlooked. Accessing the right kind of support is particularly difficult for:

- black, asian and minority ethnic (BAME) communities;
- people who identify as lesbian, gay, bisexual, or transgender (LGBTIQ+);
- older and younger age groups;
- women;
- people with physical and sensory disabilities;
- people with long term/physical health conditions;
- people with complex needs – for example those who are homeless and/or have drug or alcohol addictions.

For people with intersecting identities, such as BAME people who are gay and/or disabled, it is often even more difficult to access the right kind of support from mainstream services.²¹

The NHS England No Assumptions guidance, developed with National Voices, Think Local Act Personal with the support of NSUN, states that to be effective, personalised, co-ordinated support in mental health needs to be responsive to the following 'I' statements:

- My culture and identity are understood and respected when I am in contact with services and professionals.
- The strengths of my culture and identity are recognised as part of my recovery
- I can find peer support from people who understand my culture and identity.
- I am not stigmatised by services and professionals as a result of my health symptoms or my cultural or ethnic background.²²

However, for groups and individuals who are socially marginalised, accessing mental health services is extremely difficult within the wider context of social and structural injustice. Evidence shows that a high percentage experience discrimination from people working in the health system.²³ It also shows that people's own understanding of and approaches to their mental health and wellbeing is not being included in recovery and care plans, particularly highlighted as a problem for BAME people.²⁴

Because mainstream services have often been unresponsive to the strengths, knowledge and particular needs of people from socially deprived or marginalised communities, local grassroots and independent community-led support initiatives have evolved in response to unmet need and to build on people's capacity for mutual support. These initiatives can offer types of social, emotional, mutual, cultural and identity-related support that mainstream services cannot and so require sustained, strategic investment.²⁵

More needs to be done to:

- Support and invest in the work and sustainability of local grassroots, specialist and community groups or user-led organisations
- Support and invest in user-led research to evaluate the difference alternatives to psychiatry and community-based specialist support can make
- Ensure there are community-based alternatives to medication and psychiatry that encourage people from marginalised communities to get the right help sooner

nsun will:

- **Work with the most marginalised, deprived and isolated individuals and groups to ensure the membership truly represents the diversity of people with experience of mental distress.**
- **Ensure messages and presentation of information expresses 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.**
- **Deliver training and organise events based on membership requests.**
- **Facilitate local leadership programmes.**

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- Ensure that effective complex needs services are in place across the country for people from marginalised communities who have a 'dual diagnosis' (mental health and addictions.)

There needs to be better service provision for young people (particularly those who have been in care), older people, mothers who need to access specialist perinatal mental health community services, and people who are in prison and experiencing mental distress.

We believe that:

- There must be greater recognition of and response to the diversity of people with lived experience, their views and experiences
- This means that everyone's voice should be heard and responded to, including BAME and LGBTIQ+ communities, other socially deprived or marginalised groups and the many people who are not reached by traditional communication channels

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5. CHALLENGE INSTITUTIONALISED DISCRIMINATION AND PUT EQUALITY BACK ON THE AGENDA FOR MAINSTREAM MENTAL HEALTH SERVICES

The Equality Act (2010) makes it unlawful to discriminate against people with a 'protected characteristic' (age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; sexual orientation). Institutionalised discrimination and serious, damaging inequalities still exist within mainstream mental health services, particularly in inpatient settings. Discrimination, oppression and inequality need to be continually monitored and proactively addressed with service users, survivors, their communities and organisations. Mental health services must be held to account under the Act.

The benefits of working across equality issues have been acknowledged, however concern has been expressed that this should not lead to the neglect of unique issues for the individual communities and people with protected characteristics under the Act.²⁶ Further work also needs to be carried out with regard to how these protected characteristics intersect and affect discrimination that is experienced in services, wider society and impacts on mental health.²⁷

Following the death of David Bennett in 1998, the Delivering Race Equality programme was set up to address institutional racism within the NHS.²⁸ 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.²⁹

Institutional discrimination also exists for LGBTIQ+ people.³⁰ LGBTIQ+ people are more likely to develop mental health issues and are at a higher risk of suicide and self-harm.³¹ There continue to be concerns about 'reparative' therapy (which aims to change sexual orientation or reduce attraction to others of the same sex) resulting in a Department of Health-led consensus statement against the practice.³² Evidence suggests that recent public spending cuts and welfare reforms are reversing the very recent health equality gains made by LGBTIQ+ people.³³

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.³⁴ Important lessons and guidelines from the National Mental Health Development Unit and the Department of Health equality programmes do not appear to have had as much impact on improving mental health as they should have done.

Funding cuts have also affected many BAME and LGBTIQ+ organisations and projects.^{35 36} The Council of Ethnic Minority Voluntary Sector Organisations has found that although requests for services have increased by 77%, 45% of BAME third sector groups have faced funding cuts from local authorities and 61% from government and grant funds. Research by National Centre for Social Research and Unison reports that LGBTIQ+ community organisations have been disproportionately affected by public spending cuts, were less of a priority for both public and charitable funding and that LGBTIQ+ issues were at risk of being marginalised in equality initiatives (Davies et al, 2016).

With regard to 'service user involvement' people with lived experience from racialised communities often experience 'involvement' as tokenistic, or by proxy: through the involvement of community 'leaders'; the BAME voluntary sector; through professionals or family members.³⁷ User/survivor groups and individuals from racialised communities often work in isolation and with limited resources. They are often marginalised within the predominantly white user/survivor movement.

LGBTIQ+ people consistently report invisibility or marginalisation in involvement and equality initiatives, as well as fear of discrimination in user groups.³⁸



- **Commit resources and develop work that sees BAME and LGBTIQ+ service users and survivors taking the lead and participating in meaningful involvement;**
- **Aim to work directly with BAME and LGBTIQ+ groups and individuals to ensure that the membership truly represents the diversity of people with experience of mental distress;**
- **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.**

6. CALL FOR A REFORM OF THE MENTAL HEALTH ACT 2007 TO MAKE IT FULLY COMPLIANT WITH HUMAN RIGHTS LEGISLATION AND ENSURE THAT PEOPLE ARE NOT HARMED OR ABUSED

Receiving a psychiatric diagnosis and being on the receiving end of mental health services continues to be a harmful experience for many people. All too frequently it can lead to discrimination, isolation and a loss of autonomy.

Coercion and restraint practices continue to be legitimised even though they have been consistently shown to traumatise and cause harm. 38 restraint-related deaths have been recorded in the UK since 1988, 15 of which have been people from BAME communities.³⁹ In 2014 the Department of Health launched the two-year government programme 'Positive and Safe' in order to reduce the need for physical restraint.

However, a recent NSUN survey (2016) found that 65% (n=34) of the respondents stated that their most recent experience of restraint had felt like an act of aggression 'a great deal' or 'a lot'.⁴⁰ 40% (n=23) of the respondents reported incidents of restraint that occurred within the last 2 years. These findings echo the CQC State of Care report (2015/16) which states that they continue to be "concerned that we are still finding variation in the way that the MHA [Mental Health Act] and Code of Practice are being applied".⁴¹

We believe that:

- The human rights of people with lived experience should be respected and upheld and our power and choices should be returned to us
- The Mental Health Act (2007) is out of date and there is a tension between the Human Rights Act (1998) and the Mental Health Act
- Lived experience and survivor knowledge should be valued as part of the 'evidence base' that is used to inform research and decisions made by policy makers and commissioners.

nsun will:

- Campaign to radically reform the Mental Health Act (2007) to make the provisions of the UN Convention on the Rights of Persons with Disability (UNCRPD) a reality for people with lived experience of mental distress, as part of the wider disability community
- Campaign to ensure that statutory services are complying with human rights legislation and regulators are enforcing and prosecuting breaches of human rights (eg. ill-treatment or wilful neglect under section 127 of the Mental Health Act or section 44 of the Mental Capacity Act 2005).
- Create resources so that people can use a rights-based approach to challenge their sectioning.

7. REFLECT THE SOCIAL MODEL OF DISABILITY AND PROMOTE INFORMED CHOICE AND ALTERNATIVES TO MEDICATION

Mental health continues to be understood within a medical framework. Led by professionals, this approach places people into medicalised diagnostic categories and provides treatment that is based on drugs and hospital provision. NSUN's work is underpinned by the social model of disability. Without being prescriptive we seek to find alternatives to the medical model of 'mental illness'.

We believe that:

- A person-centred approach should provide us with information so that we can make informed decisions about our own lives. This includes whether to use medication or not
- A choice of support options should be available, as well as a choice of service provider (in parity with physical health)
- 'Recovery' should be personalised and defined by the individual. We reject the ways in which the term has been redefined within neoliberalism and support people with lived experience who use the term 'UnRecovered' in order to emphasise the political and social contrast to 'Recovered'
- There should be a greater recognition that there is no 'one size fits all' answer or approach
- Support should be constantly evolving on the basis of emerging evidence from lived experience
- More money should be invested in long term talking treatments and alternative therapies that are developed and delivered by people with lived experience of mental distress.

nsun will:

- **Support people to lead the agenda rather than respond to it, through the production of the Members' Manifesto**
- **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 level, 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.

8. RECLAIM, CHALLENGE AND REVIVE SURVIVOR KNOWLEDGE

Mental health research continues to exclude people with lived experience from the process of knowledge production and studies that focus on the perspectives of survivors and people who use services. Survivors also continue to be marginalised within mainstream mental health research.

Although mental health research continues to be dominated by clinical studies and quantitative methodologies, we know that a very different kind of evidence emerges when user/survivor generated philosophies and methodologies are employed.^{42 43} NSUN believes that is important to support the development of theories, methodologies and evidence generated by people with lived experience.

We need to reclaim, challenge and revive survivor knowledge by:

- Addressing issues arising from the co-option of service user research into public and patient involvement initiatives by the NHS, academia and large corporate mental health charities.
- Addressing the broader social issues of marginalisation, oppression, inequality and impoverishment, and question the relationship between deepening inequalities and mental health in research and knowledge production
- Critically examining survivor research and knowledge itself, particularly when much of the (known) history of the movement is white and 'heteronormative'.⁴⁴

nsun will:

- **Sustain and develop the Survivor Researcher Network (SRN) to provide survivor researchers a forum for networking, sharing information and supporting each other.**
- **Challenge the hierarchy of evidence and promote the validity of experiential and survivor knowledge, qualitative and emancipatory research methods**
- **Promote authentic and influential service user and survivor involvement and leadership in research**
- **Continue to seek new partnerships with other organisations and institutions to increase opportunities for SRN members and for co-production and involvement in research.**

Notes

Page 2 MEMBERS MANIFESTO

¹ Many of our members describe themselves as 'survivors', not only of the effects of mental distress, but 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 both terms in this document, we also 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. <http://www.nsun.org.uk/assets/downloadableFiles/4Pi-LANGUAGEOFMENTALWELLBEING.V42.pdf>

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² Mental Health Taskforce (2016) The Five Year Forward View for Mental Health www.england.nhs.uk/mentalhealth/taskforce/

³ See also the Fundamental Facts About Mental Health report (2016) which states that "certain population subgroups are at higher risk of mental health problems because of greater exposure and vulnerability to unfavourable social, economic and environmental circumstances, which intersect with factors including gender, ethnicity and disability"(p.8). Fundamental Facts About Mental Health 2016 (2016) London: Mental Health Foundation.

⁴ 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

⁵ Davies, M., H. Porter and M. Mitchell (2016) Implications of reductions to public spending on LGBTIQ+ and services. London: NatCen.

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⁶ 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

⁷ Thomas, P. (2015) Austerity, Government

Economic Policy and Recovery <http://www.bridgecollective.org.uk/wp-content/uploads/2016/04/Austerity-government-economic-policy-recovery-Apr-2016.pdf>

⁸ *ibid*.

⁹ Slade, M., M. Amering, M. Farkas et al (2014) Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems World Psychiatry 13(1) pp.12-20.

¹⁰ Deegan, P. (1987) Recovery, Rehabilitation and the Conspiracy of Hope https://www.patdeegan.com/sites/default/files/files/conspiracy_of_hope.pdf

¹¹ <https://recoveryinthebin.org/recovery-in-the-bin-19-principles/>

Page 6 2. MAKE THE POLICY OF 'GETTING THE RIGHT SUPPORT, AT THE RIGHT TIME, IN THE RIGHT PLACE, FROM THE RIGHT PERSON' A REALITY

¹² 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>

¹³ 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>

and National Voices and Think Local Act Personal (2014) No Assumptions: A narrative for personalised co-ordinated care and support in Mental Health, NHS England - Strategic Partners Programme. http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/les/noassumptionsnal27_august.pdf

¹⁴ Care Quality Commission (2016) The State of Health Care and Adult Social Care in England 2015/16 (p.12). Newcastle: Care Quality Commission. http://www.cqc.org.uk/sites/default/files/20161013_stateofcare1516_web.pdf

Page 7 3. PRESSURE MENTAL HEALTH SERVICES TO MAKE THE PRINCIPLE OF 'NOTHING ABOUT US WITHOUT US' A REALITY AT ALL LEVELS, THROUGH MEANINGFUL INVOLVEMENT IN DECISIONS ABOUT OUR OWN INDIVIDUAL

CARE AND GENUINE CO-PRODUCTION TO DEVELOP SERVICES

¹⁵ 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://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170701/Patients_First_and_Foremost.pdf

¹⁶ Carr, S. (2016) Position Paper: Are mainstream mental health services ready to progress transformative co-production? Bath: NDTi

¹⁷ Crepaz-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

¹⁸ 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>

¹⁹ National Development Team for Inclusion (NDTi) (2016) Progressing transformative co-production in mental health, Bath: NDTi http://www.ndti.org.uk/uploads/files/MH_Coproduction_guide.pdf

²⁰ National Survivor User Network (2014) 4Pi National Involvement Standards: Executive Summary. <http://www.nsun.org.uk/assets/downloadableFiles/4pi.-ni-standards-for-web.pdf>

Page 8 4. WORK TOGETHER WITH PEOPLE FROM SOCIALLY DEPRIVED AND MARGINALISED COMMUNITIES TO DETERMINE THEIR SUPPORT AND DEVELOP ALTERNATIVES

²¹ Carr, S. (2010) Seldom heard or frequently ignored? Lesbian, gay and bisexual (LGB) perspectives on mental health services, Ethnicity and Inequalities in Health and Social Care 3(3): 14-23.

²² National Voices and Think Local Act Personal (2014) No Assumptions: A narrative for personalised co-ordinated care and support in Mental Health, NHS England - Strategic Partners Programme. <http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/les/noassumptions>

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²³ 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

²⁴ 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

²⁵ Carr, S. (2014) HSMC Policy Paper 18: Social Care for Marginalised Communities: Balancing self- organisation, micro-provision and mainstream support Birmingham: University of Birmingham

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5. CHALLENGE INSTITUTIONALISED DISCRIMINATION AND PUT EQUALITY BACK ON THE AGENDA FOR MAINSTREAM MENTAL HEALTH SERVICES

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³⁰ Somerville, C. (2015) Unhealthy Attitudes: The treatment of LGBT people in health and social care services. London: Stonewall. http://www.stonewall.org.uk/sites/default/files/unhealthy_attitudes.pdf

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³² UK Council for Psychotherapy (2014) Conversion therapy consensus statement. London: UK Council for Psychotherapy. http://www.psychotherapy.org.uk/UKCP_Documents/policy/Conversion%20therapy.pdf

³³ Davies, M., H. Porter and M. Mitchell (2016) Implications of reductions to public spending on LGB & T people & services London: NatCen.

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³⁷ Kalathil, J. (2013) Dancing to our own tunes: reprint of the 2008 report with a review of work undertaking to take the recommendations forward, London: National Survivor User Network. <http://www.nsun.org.uk/assets/downloadableFiles/dtoots-report---for-website2.pdf>

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6. CALL FOR A REFORM OF THE MENTAL HEALTH ACT 2007 TO MAKE IT FULLY COMPLIANT WITH HUMAN RIGHTS LEGISLATION AND ENSURE THAT PEOPLE

ARE NOT HARMED OR ABUSED

³⁹ Duxbury, J., F. Aiken and C. Dale (2011) 'Deaths in custody: the role of restraint', *Journal of Learning Disabilities and Offending Behaviour*, 2(4): 178 – 189.

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8. RECLAIM, CHALLENGE AND REVIVE SURVIVOR KNOWLEDGE

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⁴⁴ Heteronormativity denotes or relates to a world view that promotes heterosexuality as the normal or preferred sexual orientation.

**Together we
are stronger**



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