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Members' manifesto

a social revolution in mental health
user led - user controlled - user commissioned

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We call on the next government to:

1. **Make the principle of 'nothing about us without us' a reality** through effective and meaningful involvement in all aspects of our lives

2. **Reform the Mental Health Act 2007** to make it fully compliant with human rights legislation and ensure that people are not harmed or abused by restrictive practice

3. **Provide alternatives to medication,** and reflect the social model of disability, in better person-centred support

4. **Ensure access to timely and appropriate resources and support**

5. **Meet the needs of people with lived experience of mental distress from marginalised communities**

6. **Address the injustice and harm that have been caused by cuts to public funding** and changes to the benefits system

7. **Recognise and invest in research** and training initiatives that are service user-controlled/user-led

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The National Survivor User Network (NSUN) is an independent, service user/survivor led and controlled charity that connects people with lived experience of mental distress to give us a stronger voice in shaping policy and services. We seek to create a strong, sustainable and influential network of individuals and groups of people with lived experience who communicate with and support each other.

In this manifesto, we outline what the next government should do based on what our members have told us. We have used feedback from our AGM (January 2015), the top ten list of issues identified by members in our annual survey (2013 and 2014), and responses from members to a direct request asking what should be in NSUN's manifesto.

Mental health care accounts for only 13% of the NHS budget and despite a growing need for services funding has been cut for three years in a row.[ii] The Mental Health Policy Group (comprised of the Centre for Mental Health, Mental Health Foundation, Mental Health Network, Mind, Rethink and the Royal College of Psychiatrists) has recently published their Manifesto for Better Mental Health. They call for the next government to increase funding for mental health services and state that:

"All national and local decisions – including funding – must be consistent with legal requirements to promote both the mental and physical health of every citizen, often referred to as 'parity of esteem'.[iii]"

Investment in mental health services is vital and a theme that runs throughout our manifesto. However, we believe that 'parity of esteem' should not simply apply to the equal treatment of conditions but to the equal treatment of people, which means paying attention to their views.

With over 4,000 members, NSUN is able to piece together a national picture of mental health services and support. Across the country, our members continue to report experiences of a mental health system where people face an ongoing battle to exert control and to establish and exercise basic rights.

1. Make the principle of 'nothing about us without us' a reality through effective and meaningful involvement in all aspects of our lives

"We need to be involved at the very beginning, with the development of the service rather than just delivery." Quote from 4Pi National Involvement Standards consultation, 2014

Policy makers have increasingly acknowledged that people should be placed at the centre of their care, and their opinions should be heard, respected and acted upon.[iv] For example, the No Health without Mental Health (2011) cross-governmental strategy was underpinned by the principle of 'no decisions about me, without me.'[v]

However, although the involvement of people who use services has been legislated for, it is still not practised as the norm, as highlighted by the Francis Report. Drawing on

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a growing body of research around effective involvement,[vii viii] 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 partnership working 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 states that involvement benefits from the following shared principles and values:

A commitment to:

- improve services and improve the wellbeing and recovery 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 of 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.[ix]

In practice, this means that the next government should:

- encourage services and organisations to endorse the 4Pi National Involvement Standards and commit to these principles and values.

2. Reform the Mental Health Act 2007 to make it fully compliant with human rights legislation and ensure that people with lived experience of mental distress are not harmed or abused by restrictive practice

"Inpatient wards should be places of dignity and safety."
Quote from AGM, 2015

"Physical restraint can cause unnecessary distress on the mind… Service users should not be abused by Compulsory Treatment Orders that can often cause unnecessary distress (and possibly suicide) and hinder recovery."
Manifesto consultation, 2015

Receiving a psychiatric diagnosis and being on the receiving end of mental health services continues to be a harmful experience for

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many people. All too frequently it can lead to discrimination, isolation, a loss of autonomy and the right to self-representation.

Over the last few decades, people who have been labelled as 'mad' or 'mentally ill' have spoken up about their experiences and begun to assert their human rights. Although progress has been made with regard to 'user involvement' in policy and legislation, the next government needs to move beyond the superficial rhetoric of 'empowerment' and 'choice' and take action to ensure that people with lived experience of mental distress are genuinely respected, valued and have power and influence.

We believe that:

- The human rights of people with lived experience should be respected and upheld, and their power and choices returned to them.

- 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 should be valued as part of the 'evidence base' that is used to inform decisions made by policy makers and commissioners.

- There must be a greater recognition and appreciation of the diversity of people with lived experience, their views and experiences.

- This means that everyone's voice should be heard and responded to, including BME and LGBT communities, other marginalised groups and the many not reached by traditional communication channels.

In practice this means that the next government should:

- address the UN Convention on the Rights of Persons with Disability (UNCRPD,) by abolishing or reforming the Mental Health Act (2007) to make the provisions of the UNCRPD a reality for people with lived experience of mental distress, as part of the wider disability community;

- ensure that statutory services are complying with human rights legislation and regulators are enforcing and prosecuting breaches of human rights (e.g. ill-treatment or wilful neglect under section 127 of the Mental Health Act or section 44 of the Mental Capacity Act 2005).

3. Provide alternatives to medication, and reflect the social model of disability, in better person-centred support

"Access to peer support should be provided. That's what made the most difference for me. It does need to be enabled though. Peer supporters can be exploited and expected to work for nothing."
Quote from Manifesto consultation, 2015

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

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and hospital provision. NSUN's work is underpinned by the social model of disability.[x] Without being prescriptive we seek to find alternatives to the medical model of 'mental illness.'

We believe that:

- A person-centred approach should provide people with information to make informed decisions about their own lives. This includes making choices about 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' can have different meanings for mental health professionals and people with lived experience. For example, many people who use services have raised the issue that their understanding of recovery does not fit with ideas of recovery as framed by the mental health service.[xi] Recovery should therefore be personalised and defined by the individual.

- There should also be 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.

In practice, this means that the next government should:

- invest more money in long term talking treatments and alternative therapies developed and delivered by people with lived experience of mental distress;

- offer a whole range of talking treatments, not just cognitive behavioural therapy;

- fund more self-defined recovery and self-management projects;

- promote peer support models and validate and employ peer support workers;

- work towards the integration of mental and physical health services to create a more holistic model of care and reduce stigma.

4. Ensure access to timely and appropriate resources and support

"I think the government should make mental health a priority in healthcare. You are put on a waiting list and just ignored until you reach the top of that list (which can be months or even years.) In other areas of health there are time limits for waiting lists. In mental health this is not the case, why not?"
Quote from Manifesto consultation, 2015

The National Institute for Health and Care Excellence (NICE) Quality Standard 14 sets out guidelines for 'service user experiences' in adult mental health.[xii] It details the importance of timely appointments, empathic staff, shared decision-making, clear information and support options. However, we know that this is not the experience of many people who have used mental health services.

We believe that the next government should:

- reduce waiting times for mental health services;

- provide access to 24/7 crisis services;

- address the number of 'revolving door' patients who are discharged before they

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are ready and who do not have recourse to support on discharge;

- improve community mental health and early intervention services for young people and adults;

- improve transitions between child and adolescent mental health services;

- provide access to and clear information about personal budgets;

- provide consistent mental health services by sharing and replicating good practice across the country;

- provide 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 to providing a place of safety;

- ensure integrated health and social services pathways, to provide necessary housing, physical health services and other support, particularly when transitioning from Inpatient care.

5. Meet the needs of people with lived experience of mental distress from marginalised communities

"I am an African woman, aged 54 years old and have mental health problems. As a BME I face daily discrimination because I am a migrant, and have suffered Race Hate/ Harassment for many years…

The mental health system stigmatises us and does not treat us with the respect and dignity that we deserve – just like any other citizen in Britain who has a disability. Access to every service is fraught with barriers that exclude us at every turn."
Quote from Member Survey, 2013.

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 and minority ethnic (BME) communities;

- older and younger age groups;

- women;

- people with physical and sensory disabilities;

- people with long term/physical health conditions;

- people who identify as lesbian, gay, bisexual, or transgender (LGBT);

- people with complex needs – for example those who are homeless and/or have drug or alcohol addictions.

The NHS England No Assumptions guidance, developed with National Voices and Think Local Act Personal, states that personalised, co-ordinated support in mental health should consider 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.

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- 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.[xiii]

However, for groups and individuals who are already 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, making them reluctant to engage to obtain the support and help they need.[xiv]

Dancing to Our Own Tunes: Reassessing black and minority ethnic mental health service user involvement states:

'Mental health is only one aspect of a person's life. Much of the racism and discrimination that people from black and minority ethnic communities face within services is a reflection of the structural inequalities within society. In that sense, working to change mental health services has to be linked with changing the overall situation of black and other minority ethnic groups in this country.[xv] '

We believe the next government should:

- actively address and work to change the systemic injustice, racism and discrimination experienced by people from BME and other marginalised communities;

- support the work that is being done by community groups and organisations at local level;

- ensure there are alternatives to medication that might encourage people from

marginalised communities to get help sooner;

- gather monitoring information more regularly to become better informed about what services these groups currently access and what services they would like to access. For example, many monitoring forms used by the NHS do not acknowledge that people are not necessarily heterosexual, thereby preventing people from disclosing and missing opportunities to discuss what needs might be able to be met;

- 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 drug/alcohol addictions.)

6. Address the injustice and harm that have been caused by cuts to public funding and changes to the benefits system

"Sanctions/benefit cuts facing people in distress should be looked at from a totally different perspective. These are making people in distress feel worthless, useless and undoubtedly making their illness worse. Forcing people to work when they are ill is not going to make them better."

Quote from Manifesto consultation, 2015

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The case for better mental health is often framed in terms of lost productivity, benefit payments and absence from work.[xvi] This detracts from and depersonalises people who live with mental distress - the cost to the individual in terms of lack of support and suffering.

During the recent economic recession, unemployment rates of people with lived experience of mental distress have risen across Europe.[xvii] More people are experiencing mental distress as they struggle to deal with loss of a job and housing.[xviii]

The recent welfare reforms have been associated with an increase in suicide[xix] and have also become an increasing source of discrimination.[xx] People's experiences of stigma and discrimination were surveyed as a result of the Time to Change campaign. Comparing results from 2008 with 2012 showed that there was a significant increase in the discrimination experienced by people with lived experience of mental distress when claiming benefits.

We believe that:

- There should be less of a focus on economic outcomes as measures of human worth and a greater emphasis on contributions of social value.

- Recent changes to the benefits system, cuts to public funding and healthcare are subjecting people living in poverty to further disadvantage.

- The benefits system should aim to support people and facilitate their ability to work rather than hindering it with rigid sanctions and inflexible arrangements.

In practice, this means that the next government should:

- stop benefit cuts, punitive sanctions and austerity measures;

- provide more flexibility in benefit arrangements for people with lived experience who want to work but need more help and support to do so;

- address the impact of competing policies within the welfare system.

7. Recognise and invest in research and training initiatives that are service user-controlled/user-led

A recent report by the Mental Health Research Network showed that only 40% of researchers were involving people with lived experience as members of their trial steering committee or project steering group. Only 20% were involving people who had used services as co-researchers or as members of advisory panels.[xxi] Less than 20% consulted with service users at the design stage.[xxii xxiii] Moreover, comparatively little user-controlled research exists.[xxiv] There also continues to be a 'hierarchy of evidence' in research, where user-led, experiential research is seen as less valid and useful than other types of research.

In addition to further investment in user-controlled and co-produced research, we believe there should be:

- further investment into qualitative methodologies that prioritise the experiences and opinions of people with lived experience;

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- more research into, and information on, the long-term effects of medication and poor efficacy;

- more training in diversity on mental health in workplaces and with commissioners, GP's and practitioners;

- mental health education in schools, backed by training and support for school staff and parents;

- training for carers, volunteers and mental health workers;

- all training should be co-designed by and delivered with people with lived experience. User-facilitated training should also be developed.

End notes & references

[i] The language of mental wellbeing or 'mental health' is complex, diverse and emotive. It arises from and changes in response to different social and historic contexts, often reflecting or challenging political policies or movements. Many terms such as 'recovery', 'co-production', 'choice', 'empowerment' and 'respect' are used within dominant policy discourses. For some, such terms have become meaningless due to the ever-widening gap between rhetoric and reality. When we refer to these terms in this manifesto our concern throughout is with what is meaningful, genuine and defined by people with lived experience.
For further information see: http://www.nsun.org.uk/assets/downloadableFiles/NIPTheLanguageofMentalWellbeing2.pdf

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[iii] As above.

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[ix] National Survivor User Network (2014) *4Pi National Involvement Standards: Executive Summary*. http://www.nsun.org.uk/assets/downloadableFiles/4PINationalInvolvementStandards-A4ExecutiveSummary-201532.pdf

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[xii] 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

[xiii] 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/files/noassumptionsfinal27_august.pdf

[xiv] 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

[xv] 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

[xvi] OECD (2014) *UK needs to tackle high cost of mental-ill health*, says OECD. http://www.oecd.org/els/emp/uk-needs-to-tackle-high-cost-of-mental-ill-health.htm

[xvii] Carr, S. (2014) *Crisis, what crisis? EU-wide data shows negative impact of the recession on people with mental health problems*. http://www.thementalelf.net/populations-and-settings/poverty/crisis-what-crisis-eu-wide-data-shows-negative-impacts-of-the-recession-on-people-with-mental-health-problems/

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[xxi] It is worth noting however that these roles are not equivalent and that advisory panel members have a more limited role than that of a co-researcher.

[xxii] Staley, K (2012) An evaluation of service user involvement in studies adopted by the Mental Health Research Network. MHRN & NIHR.

[xxiii] The MHRN has now been replaced by the Clinical Research Network: Mental Health.

[xxiv] Staddon. P (ed) (2013) Mental health service users in research: critical sociological perspectives, Bristol: Policy Press. ●

We will strive to be a lively and distinctive network that matches the unique, user-led approach and convention-challenging aspirations of our members.

together we are stronger

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