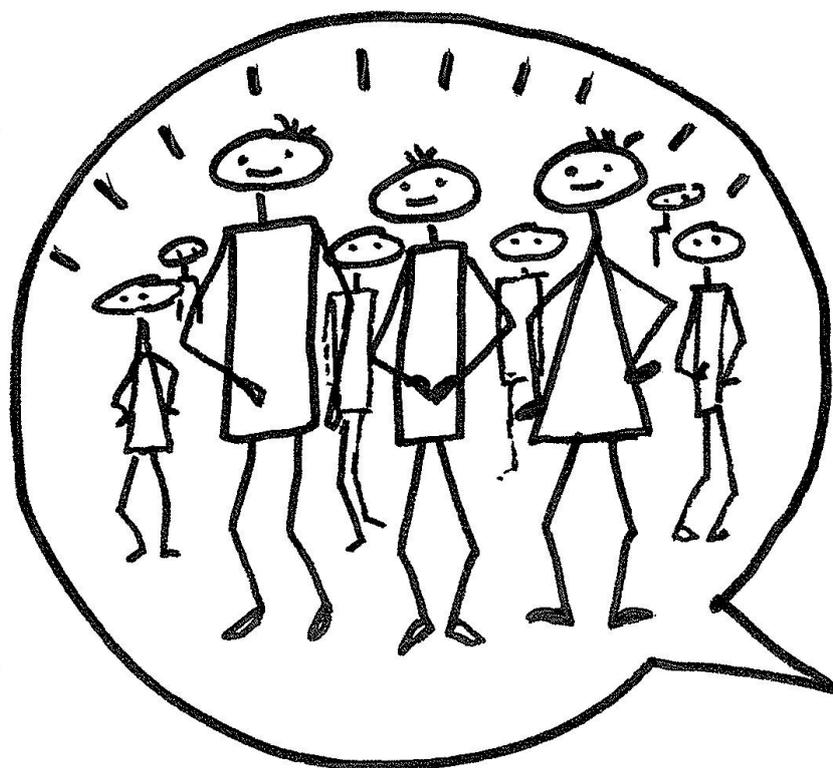


# Person centred care 2020:

## Calls and contributions from health and social care charities



**National Voices**

People shaping health and social care

Published September 2014

## Section 1: Summary

### The ambition: person centred care by 2020

The health and care services of which this country is so proud are under increasing pressure and not doing well enough. Progress towards the policy goal of “putting people first” is too slow, and health inequalities are a neglected scandal. We deserve better.

The national charity coalition National Voices and its members – some 140 of England’s leading national health and social care charities – want the health and care systems in England, led by government, to set an urgent ambition to achieve genuinely person centred care by 2020. This would improve the quality of life, health and wellbeing of people, and make care systems more sustainable.

This document sets out calls for action, based on sound evidence, and highlights the crucial contributions that our sector – the voluntary and community sector (VCS) – can make, with the right support. In summary we call for the following:

1. **Target public health.** England is not doing enough to prevent ill health. We need a renewed, nationally led drive to reduce harm from smoking, drinking, poor lifestyle and wider causes of poor health, focused on those with the greatest burdens and risks of ill health. (Sections 4 and 5).
2. **Make people the priority, not the system.** Professional and organisational priorities routinely trump the priorities of people who use services, their carers and families. In its extreme form this leads to outrages like mid-Staffordshire and Winterbourne View. ‘What matters to people’ should be one of the key organising principles for services. (Section 4).
3. **Support people with chronic conditions and disabilities.** We call for investment in proven ways of enhancing people’s health and quality of life: shared treatment decisions; supported self-management; training for health staff in person centred care; access to health records; peer support; personal budgets; and widespread use of care and support planning. (Sections 2 and 3).
4. **Create people-powered services.** Statutory services cannot fix everything. It is time to recognise, support and invest in the huge contribution of carers, volunteers, engaged citizens and the voluntary and community sector in helping individuals and shaping services. It is time to work with citizens and communities as equals. This requires a shift in mind-set, behaviours and processes. (Sections 4 and 5).
5. **Fund health and care properly.** The next government must guarantee a five year settlement for health and social care, with real terms increases in public funding, including for the contributions of the VCS. This is essential to enable the transformation of care we seek. Without this settlement the fundamental principles

of the NHS will be undermined and the policy goals of the Care Act 2014 will be unachievable. (Section 6).

6. **No more top-down reorganisations.** These are distracting, morale-sapping and wasteful. The next government should set the direction for person-centred care. It should create consistent incentives for health, social care, VCS and other services to come together, in locally suitable ways, moving towards integrated budgets and commissioning. It should support devolved leadership while ensuring there is clear accountability for local performance. (Section 5).

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## Section 2: Introduction: the need for person centred care

There is much to be proud of in the English NHS and wider systems of health and care, which compare well with other countries<sup>1</sup>. But these systems are under increasing pressure and not doing well enough. People who need services and support, their carers and families deserve better.

This document sets out what the health and social care charities who are members of National Voices want to see by 2020.

It sets out an ambition and proposals for creating genuinely **person centred care**, drawing on the work of National Voices and its members over several years (more detail in the Appendix) and on a substantial body of [evidence](#).

“**Putting patients first**” has become a health policy mantra in recent years, but reality lags behind rhetoric. There have been successive waves of confusing structural reorganisation, by the current and previous administrations. There has also been an unprecedented period of public spending constraint in health and especially social care. The result is an increasingly disjointed, over-stretched system of services and support.

Patients, families and communities have too little say, especially the most vulnerable. There is a massive and relatively neglected problem of health inequalities which leads to many people suffering ill health and dying years prematurely. Many battle with services which are frustratingly and sometimes dangerously fragmented. The government goal of “**parity of esteem**” for mental health has not stopped mental health services becoming over-stretched and under-funded. Many people face inequalities of access because they are from marginalised communities or have certain rare, complex or stigmatised conditions.

A failure to listen to and involve patients and their families – as well as front line staff – has been identified as one of the main failings in the scandals at **Mid-Staffordshire NHS Trust**, **Winterbourne View**, and in other analyses of poor care.<sup>2 3 4</sup>

Quality of care is too variable, people’s experiences are often poor and standard models of care – often reactive, episodic and narrowly medical – are increasingly out of kilter with the needs of the growing number of people with chronic health problems and disabilities, who deserve a more holistic, personalised offer – in short, **person-centred coordinated care**.

The public spending squeeze means that many of the key components of person centred coordinated care are being **increasingly rationed** as set out in Section 6.

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<sup>1</sup> See for example this report from the Commonwealth Fund <http://www.commonwealthfund.org/publications/fund-reports/2014/jun/mirror-mirror>

<sup>2</sup> See: [http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/not\\_the\\_francis\\_report\\_final.pdf](http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/not_the_francis_report_final.pdf)

<sup>3</sup> See: [http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/after\\_the\\_francis\\_report\\_2.pdf](http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/after_the_francis_report_2.pdf)

<sup>4</sup> ‘A promise to learn: a commitment to act’, Berwick, B, DH 2013: <https://www.gov.uk/government/publications/berwick-review-into-patient-safety>

Despite these problems there is also cause for optimism. During the current Parliament a cross-party consensus emerged about the importance of person centred, coordinated care<sup>5</sup> for those with continuing and complex needs. Some important trials of this approach are underway, for example, through the integrated care pioneer programme.

The **Care Act 2014** has put social care on a modern legislative foundation, with a focus on prevention and wellbeing.

A broader consensus is emerging about how to transform systems to meet current and future challenges. The **2015 Challenge Partnership**, of which National Voices is a member, has laid out [seven challenges](#) for national leaders to address.

There have been various other developments in this Parliament aimed at strengthening the citizen voice in health and care. Though welcome, they have often been pursued as unconnected initiatives, and it is too early to assess their impact.

This National Voices document has developed from discussions at our annual members' conference in March 2014, and has been produced in partnership with our members. Our central message to national and local leaders is: support proven, evidence based approaches which involve people in their health and care. These improve care quality and lead to better outcomes. They include:

- **genuine shared decisions about treatments**<sup>6</sup>, with routine use of patient decision aids and question prompts
- **supported self management** as a key component for people living with long term conditions and disabilities<sup>7</sup>
- **access to personal records** – this is do-able now, and proven to support self management, shared decisions and people's commitment to courses of prevention and treatment<sup>8</sup>
- **personal budgets** to hand people greater control over the way they maintain their health and wellbeing<sup>9</sup>
- **training and development in the skills required for person centred care** for large cohorts of clinicians – such as health coaching, motivational interviewing, risk communication<sup>10</sup> and eliciting people's values and preferences<sup>11</sup>

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<sup>5</sup> The Narrative for person centred coordinated care, produced by National Voices and TLAP and adopted as the system-wide definition of the goals of integrated care, has been instrumental in this. See the Appendix.

<sup>6</sup> See: [http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/supporting\\_shared\\_decision-making.pdf](http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/supporting_shared_decision-making.pdf)

<sup>7</sup> See: [http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/supporting\\_self-management.pdf](http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/supporting_self-management.pdf)

<sup>8</sup> The Department of Health's Information Strategy 2013, handed over to NHS England, promised online access to GP records for all by 2015:

<http://webarchive.nationalarchives.gov.uk/20130802094648/http://informationstrategy.dh.gov.uk/category/case-studies/me-and-my-care/>

<sup>9</sup> Over 60 per cent of social care personal budget holders reported a positive impact on control over important things in life, and control over their support. See: <http://www.thinklocalactpersonal.org.uk/library/POETSummaryFINAL.pdf>

<sup>10</sup> For discussions of communicating risk and the techniques that work see for example: Peters, E et al, 'Numeracy Skill And The Communication, Comprehension, And Use Of Risk-Benefit Information', Health Affairs, May 2007 vol. 26 no. 3 741-748; Apter, A et al, 'Numeracy and Communication with Patients: They Are Counting on Us', J Gen Intern

and, as a key delivery mechanism to achieve all these –

- **genuine care and support planning**, using principles and steps outlined by [National Voices](#) and others<sup>12</sup>.

These changes can be made locally, but there is a need for some national programmes – for example, to develop and produce patient decision aids, to improve people’s health literacy (which is a major barrier to their success), and spread good practice in care and support planning. Government should either lead or ensure that arm’s-length bodies are leading these programmes, learning from other countries’ experience, for example in some states of the US<sup>13</sup>, and Scotland<sup>14</sup>.

National leadership is also essential for people with rare and complex conditions, for example to ensure that nationally commissioned specialist services are well integrated with local non-specialist services<sup>15</sup>.

In subsequent sections, we set out what these changes would look like for patients, service users and carers; how services would need to be organised; how reform should be tackled and what the next government should do – and not do.

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Med. Dec 2008; 23(12): 2117–2124. In a UK context, ‘Health Literacy’, RCGP 2014 suggests one third of UK adults fail to understand numerical information presented to them:

<http://www.rcgp.org.uk/news/2014/june/~media/Files/Policy/RCGP-Health-Literacy-2014.ashx>

<sup>11</sup> These skills should not be seen as ‘downstream’ of system change but as a *pre-requisite*, and should not be put on hold pending longer term adjustments to professional education curricula

<sup>12</sup> See: <http://www.nationalvoices.org.uk/what-care-and-support-planning>

<sup>13</sup> Such as states that have implemented legislation for shared decision making:

<http://www.informedmedicaldecisions.org/shared-decision-making-policy/state-legislation/>

<sup>14</sup> Person centred care was a key part of the national quality strategy for Scotland

<http://www.scotland.gov.uk/Topics/Health/Policy/Quality-Strategy>. See, among other resources, ‘GauN Yersel: the self management strategy for Scotland’, 2008: [http://www.scotland.gov.uk/Topics/Health/Support-Social-Care/Self-Management/GauN\\_Yersel](http://www.scotland.gov.uk/Topics/Health/Support-Social-Care/Self-Management/GauN_Yersel); National Health Literacy Action Group, Scotland

<http://www.scotland.gov.uk/Topics/Health/Support-Social-Care/Health-Literacy>

<sup>15</sup> See the Specialised Healthcare Alliance manifesto: <http://www.shca.info/perch/resources/shca-2015-manifesto-final.pdf>

### Section 3: What should people experience by 2020?

We know a great deal about what good care and support looks like for different groups of people, but mainstream services have struggled to incorporate this knowledge. By 2020 we think there should no longer be any excuses for failing to achieve the following:

**The values, rights and pledges in the NHS Constitution are being delivered.**

**The vast majority of people report a positive experience of care**, especially in those aspects people most value<sup>16</sup>, such as timely access to help, effective treatment, involvement in decisions, involvement of family members, empathy, respect, emotional support and continuity of care.

**Care is available as close to home as possible**, when it is needed (24/7).

**People feel both educated and empowered** to protect their health and prevent ill health; and to manage their conditions.

**People with continuing conditions, disabilities and complex needs:**

- can plan their care, support and treatment with trusted professionals and supporters
- have a known single point of contact they can turn to at any time
- have an identified care coordinator responsible and empowered to bring services together around their goals and needs
- are supported to manage their lives and conditions as successfully as possible (supported self management), by having
  - access to information, education and the support to use them, including peer support; and
  - professionals skilled in health coaching
- have access to a personal budget if they want one, and can use it across their health, care and support needs
- are regularly asked about any persistent distressing symptoms they experience, such as pain and sleeplessness, and have their answers systematically recorded.

**People, especially older people** with various conditions that constrain their lives:

- say they feel supported to be independent and to maintain their social and family connections
- report that, taken together, their care, support and treatment helps them live the life they want to live, to the best of their ability.

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<sup>16</sup> See [http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/enhancing\\_experience.pdf](http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/enhancing_experience.pdf)

### **Children and young people:**

- are comprehensively educated in school on mental, physical and sexual health
- have their mental health supported by statutory agencies, with professionals trained in awareness and early intervention
- experience a well prepared and seamless transition into adult services and continued coordinated support from a multi-disciplinary team.

### **People's mental and physical health problems are treated together<sup>17</sup>:**

- people with continuing mental illness and with learning disabilities receive regular physical health checks
- people with physical illness are treated by professionals trained in mental health awareness
- people have access to a professional who can review their various medications together
- people have access through primary care to psychiatric support
- people have access to psychological therapies that is as rapid as referral to consultants for physical health needs<sup>18</sup>.

### **People with dementia:**

- get a timely diagnosis and appropriate post-diagnostic support, with neighbourhood, community and voluntary sector assets mobilised to provide this
- live in dementia friendly communities.<sup>19</sup>

### **Carers:**

- are recognised as the backbone of the care system, as expert partners and as members of the team around the person
- are welcomed, involved and consulted in all care settings
- receive training for their role
- have increased rights to care leave and other adaptations from employers.<sup>20</sup>

**People with marginal positions in society<sup>21</sup>** are brought within the safety net of care and support, including regular access to a GP.

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<sup>17</sup> 'No Assumptions', TLAP and National Voices for NHS England, 2014

<sup>18</sup> The consensus document "[We still need to talk](#)" from the mental health sector calls for talking therapies to be available to everyone who needs them within 28 days of referral

<sup>19</sup> Dementia charities are seeking: a minimum diagnosis rate of 66% across all areas working towards 75% by 2017; time from referral to diagnosis no longer than 12 weeks; every person with dementia and their carer to have access to a Dementia Adviser; quality assured memory services.

<sup>20</sup> See: <http://www.carersuk.org/for-professionals/policy/policy-library/the-case-for-care-leave>

<sup>21</sup> These groups include homeless people, vulnerable migrants, prisoners, sex workers and Gypsies and travellers. See our position statement at

[http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/policy\\_position\\_health\\_inclusion\\_v1.1\\_0.pdf](http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/policy_position_health_inclusion_v1.1_0.pdf)

**Groups and communities with the highest burden/risk of ill health** have access to person centred coordinated care and receive tailored approaches to improve their wellbeing.

**People needing care at the end of life<sup>22</sup>:**

- have care that is better planned, with fewer unnecessary transitions between services
- experience a higher quality of care at home, in hospital and in residential homes
- have access to free (non-means-tested) social care
- can express and achieve their wishes and be involved in decisions, along with the people important to them.

**People with rare and complex conditions<sup>23</sup>:**

- have access to the specialised services they need
- are co-designers of services
- experience the effective coordination of specialised and local non-specialised services.

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<sup>22</sup> See the forthcoming 'narrative' from National Voices and the National Council for Palliative Care

<sup>23</sup> See the SHCA manifesto: <http://www.shca.info/perch/resources/shca-2015-manifesto-final.pdf>

## Section 4: How will services need to run by 2020?

To deliver genuine, person-centred care, services will increasingly need to demonstrate these key, common characteristics:

- **Much greater emphasis on promoting health and preventing illness, especially for those most at risk.** In particular this means renewed action, with national leadership, to reduce the harm from tobacco and alcohol, to promote healthier living, and to tackle wider causes of ill-health<sup>24</sup>. It means local public health services being better integrated into the planning and delivery of health services. It means strengthening the capacity of primary care to diagnose earlier and reducing inappropriate barriers to referral. It means national action to address the late diagnosis or under-diagnosis of conditions<sup>25</sup>. In all this there will be a strong, cross-government focus on improving the health of those with the largest burden of ill health, tackling the scourge of health inequalities. Currently excluded groups such as homeless people, travellers, offenders, recent migrants and others will be registered with GPs and have regular access to primary care.
- **What really matters to people will be a key outcome.** Although professionals and commissioners are increasingly discussing how to be ‘person centred’, service delivery remains dominated by regulatory, financial and organisational priorities – which regularly trump other considerations. This often results in staff doing the right things “despite the system”. At worst, it results in the fundamental neglect of people’s rights and needs as evidenced at mid-Staffordshire, Winterbourne View and in other well-documented failures of care.

Things will not change until what counts as an “outcome” is redefined, and aligned with performance monitoring, accountability and funding<sup>26</sup>. Systems need to be guided by measures of people’s fundamental goals and preferences, for example wellbeing, quality of life, mobility, independence, social connectedness and confidence to manage. These broader measures will reinforce different patterns of care: services joined up around the person, at or close to home, making the best use of both formal and informal sources of support.

- **Agencies with an impact on health and care will increasingly work together.** The ambition for person centred coordinated care does not recognise arbitrary

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<sup>24</sup> For example, Cancer Research UK wants adult smoking prevalence to be reduced to less than 15% (from 20% currently) by 2020, saving 15,000 lives per year

<sup>25</sup> Such as HIV, neurological conditions, dementia, musculoskeletal and gastrointestinal conditions. For example, in order to reduce the avoidable disability caused by late diagnosis of musculoskeletal conditions, ARMA seeks a strategic clinical network, better training for primary care professionals, and increased use of exercise prescriptions and weight reduction programmes.

<sup>26</sup> For a recent discussion of this topic see Collins, A, ‘Measuring What Really Matters’, Health Foundation, 2014 <http://www.health.org.uk/publications/measuring-what-really-matters/>

divisions of 'care' – 'care is care is care'. Local areas must develop collaborative approaches to designing and delivering services, which break down barriers between different parts of the health system and between health and social care. It will be the norm for teams of practitioners to work together regardless of whether they are in the same or separate organisations. Housing and the wider nexus of public services will be fully part of the mix, since people's homes and immediate environment have very significant impacts on health, and on their ability to manage their health, conditions and disabilities<sup>27</sup>.

- **Voluntary and community sector organisations (VCS) will be full partners in the design and delivery of person centred care.** The voluntary sector has a vital role to play in civil society generally and in health and care in particular.<sup>28</sup> The number of volunteers in health exceeds the size of the formal health and care workforce.<sup>29</sup> Voluntary organisations radically extend the range of support necessary for holistic care – for example in:

- advocacy
- information, advice and education
- practical and emotional support
- peer support
- support for people to manage their continuing conditions
- counselling and other psychological support
- befriending and organising volunteering
- building community awareness, eg in relation to health promotion, dementia, mental health, disability
- providing preventive services to targeted groups and communities
- help with recovery from physical and mental ill health, and with staying well

This work gives voluntary organisations a position of trust, expertise and access to marginalised and excluded communities. It means they are natural partners of commissioners designing and improving services; and of service providers<sup>30</sup>. Yet too many voluntary organisations, especially the smallest, report that they are side-lined by statutory agencies; disadvantaged by complex and bureaucratic procurement processes; and starved of the modest funds needed to build and maintain their capacity and to ensure their sustainability.

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<sup>27</sup> See: <http://www.cieh.org/policy/housing/poor-housing.html>

<sup>28</sup> See for example the NCVO 2015 Manifesto [http://www.ncvo.org.uk/images/documents/policy\\_and\\_research/ncvo-manifesto-2015.pdf](http://www.ncvo.org.uk/images/documents/policy_and_research/ncvo-manifesto-2015.pdf)

<sup>29</sup> King's Fund research: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/volunteering-in-health-and-social-care-kingsfund-mar13.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/volunteering-in-health-and-social-care-kingsfund-mar13.pdf)

<sup>30</sup> For a good explanation of the VCS role in needs assessment and strategy setting, for instance, see 'Comparing apples with oranges?', NHS Confederation, LGA and Regional Voices, 2014 <http://www.nhsconfed.org/resources/2014/08/comparing-apples-with-oranges>

- **Statutory services will support and enable the “informal workforce”.** People’s own behaviours and motivations; the support of family, friends, and neighbours; and the broader contributions and resources of volunteers and communities all play a huge role in promoting and maintaining health and wellbeing. Traditional, medical models of care are expensive and yet can undermine health, confidence and independence, for example for older people living with frailty. In the interests both of effectiveness and cost, statutory agencies need to move from trying to fix all problems themselves towards working with and supporting the wider “workforce” and assets of communities: working in partnership with carers; promoting self management education; providing peer support; supporting befriending; referring people to exercise groups and other health-supporting activities; and in many other ways.

## Section 5: 2020: How do we get there?

National Voices wishes to see progress through building on the best of what is happening now, and in partnership with communities, not through the kind of grand national initiatives that distract people from front line delivery, disrupt local relationships, sap professional morale and cause avoidable expense. We see the essential ingredients for reform as:

- national leadership,
- local flexibility, and
- the involvement of citizens as equals.

### **National leadership and local flexibility**

The next government should set an urgent ambition for person-centred care throughout the health and care systems and ensure that its levers – funding, incentives, regulation, mandates to arm’s-length bodies, performance monitoring, transparency and accountability – all pull in the same direction. National government:

- should do what only it can do (such as changes to national contracts; national health awareness campaigns; reforming mechanisms for citizen engagement in health bodies) while enabling devolved leadership, including the involvement of lay/citizen leaders
- should lead on public health, pushing for reductions in harm from smoking, drinking, poor diet and inactivity, and broader determinants of ill-health
- must provide stability, a guaranteed funding settlement, and adequate financing (see section 6).
- must avoid another major structural reorganisation
- should ensure that there is national leadership among the arm’s length bodies for bringing healthcare, health and social care, and the VCS together in supporting people’s health and wellbeing
- should ensure that there are national programmes, led by relevant arm’s-length bodies, on key aspects of the proven approaches to person centred care, such as health literacy, shared treatment decisions, and care and support planning
- should allow local areas the flexibility to collaborate to develop models of person-centred care, building on the best of what is happening now, with clear accountability for how well this is done.

### **Citizen involvement**

The changes we seek need to be driven by the involvement of people and communities as equals – in planning, designing, commissioning, delivering and evaluating the services they need and in social action beyond formal services.

There is increasing recognition of the power and effectiveness of such approaches, also known as “coproduction”, as reflected in the work of organisations such as NESTA and Think Local Act Personal (TLAP) and its partners.

Coproduction approaches are more likely to result in:

- renewed emphasis on health promotion, primary and secondary prevention of illness, and earlier interventions<sup>31</sup>
- services designed appropriately for the preferences of their users, and therefore used appropriately ('getting it right first time')<sup>32</sup>
- identifying and building the strengths and skills of people at an individual and community level<sup>33</sup>.

They must be distinguished from various activities pursued under the rubric of "patient and public engagement" or "consultation", which are often questionable. They are frequently framed by the perspectives and priorities of statutory agencies, give limited say, share little if any power, and often lead to little change.

Coproduction approaches need to be a strong and integral element of the design, development and improvement of services. Among the elements National Voices wishes to see pursued by commissioners are:

- **'social prescribing'**, where statutory professionals have access to, and refer people into, local community sector provision of health-supporting activities<sup>34</sup>
- use of the **Social Value Act 2012**, which requires commissioners to make building social capital in the local area a key criterion in consideration of contracts and tenders, and which was intended to open up more opportunities for social enterprises
- **community development** approaches<sup>35</sup> such as those piloted in Croydon and Halton which involve the community in identifying their needs and demands, and determining how these can be met

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<sup>31</sup> See: [http://b.3cdn.net/nefoundation/312ac8ce93a00d5973\\_3im6i6t0e.pdf](http://b.3cdn.net/nefoundation/312ac8ce93a00d5973_3im6i6t0e.pdf)

<sup>32</sup> See: [http://www.nesta.org.uk/sites/default/files/co-production\\_catalogue.pdf](http://www.nesta.org.uk/sites/default/files/co-production_catalogue.pdf)

<sup>33</sup> See above.

<sup>34</sup> See one description of social prescribing in Newcastle in The Guardian:

<http://www.theguardian.com/society/2013/nov/05/social-prescribing-fishing-group-doctor-ordered> ; and another example from Voluntary Action Rotherham <http://www.varotherham.org.uk/social-prescribing-service/>

<sup>35</sup> One definition of a comprehensive community development approach is in the framework TLAP has developed with Health and Wellbeing Boards, which includes:

- Building mutual support and self-help – developing networks and user led organisations that enable peer support and offer practical advice and support outside of formal services (e.g. experts by experience)
- Facilitating connections between individuals and resources – devising local approaches for target populations, building knowledge, confidence and skills (e.g. community connectors, local area coordination, Village Agents)
- Enabling inclusion in community activities – so that leisure, sports, social and other organisations are open to all and reach out to excluded communities to invite and encourage participation (e.g. time banking)
- Strengthening community ownership – promoting and supporting activities that bring people together to focus on particular issues (e.g. building dementia friendly communities); and

Reshaping services – both universal and targeted health and social care services to explicitly recognise coproduction and build people's confidence and skills to improve service outcomes (from redesigning streets and transport to social prescribing)

- **Investment in voluntary and community sector (VCS) infrastructure capacity** to ensure that a full range of groups and organisations can play their part in developing and providing care and support locally
- the nurturing of **user-led organisations** capable both of providing holistic and responsive care and support to people (including peer support), and of engaging in the codesign of local services more widely
- support for groups of service-**users to take control** of and lead their own care and support (for example, by collectively pooling their individual personal budgets to commission provision for a whole group)
- **Investment in patient and lay leadership** to help coproduce local strategies, plans and services and ensure a more powerful citizen voice in the governance of provider trusts, clinical commissioning groups<sup>36</sup>, health and wellbeing boards and Healthwatch.

The principle of coproduction applies equally to **national policy making**. The next government must improve its partnership working with civil society and voluntary sector organisations to develop and implement policy.

When this has worked relatively well – such as with the Care Act 2014 – better legislation and policy have resulted. Conversely, much unnecessary waste and confusion could have been avoided if similar approaches had been adopted in the period leading to the passing of the Health and Social Care Act 2012.

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<sup>36</sup> Rushcliffe CCG in south Nottingham is run by a board with a lay majority and chair; and these lay representatives sit on all sub-committees and task and finish groups, including the clinical ones. All strategies and commissioning plans are therefore explicitly backed by the CCG's patients. The lay members are voted onto the board, with every registered patient in the CCG entitled to vote; and are supported and informed by a well developed community health forum structure.

## Section 6: Funding

Austerity has taken its toll. The years of economic stagnation and public spending constraint – with their impact on income, poverty, and spending on public services and welfare – have been bad for physical and mental health.

The cap on health spending, and serious reductions in the funding and availability of social care, have meant that key elements of person centred coordinated care have been **increasingly rationed**. For example:

- GP time – for consultations and for case management – is under increasing pressure<sup>37</sup>
- There are fewer qualified district nurses working in the community<sup>38</sup>
- Social care has been drastically cut for both adults and children<sup>39</sup>
- Mental health funding is declining to an extent that some are saying is now dangerous<sup>40</sup>
- Individuals are having successful personal care packages withdrawn<sup>41</sup>
- People are having their benefits cut, capped or withdrawn<sup>42</sup>
- Affordable housing is becoming unavailable to many people<sup>43</sup>
- Local and regional infrastructure for the voluntary and community sector has been under unprecedented pressure<sup>44</sup>

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<sup>37</sup> While there were around 225 million GP consultations in 1999, estimates indicate there are now around 340 million. See: <http://www.england.nhs.uk/wp-content/uploads/2013/09/igp-cta-evid.pdf>

<sup>38</sup> See: <http://www.bbc.co.uk/news/health-22623872> which quotes figures from the Health and Social Care Information Centre, 2013. These are further quoted in Ball, J et al, *Survey of district and community nurses in 2013*, RCN 2014, as follows: ‘the number of district nurses has fallen by more than 40% in the past 15 years, with the knock on effect that whilst in 2005 district nurses made up 20% of all NHS staff recorded in the community, in 2012 only 12% of community nursing staff were qualified as district nurses’. See also ‘More than just a number’, RCN 2014 which uses HSCIC figures to show that both the total workforce and the number of advanced practitioners in community services fell between 2010 and 2013.

<sup>39</sup> ‘Since 2010 spending on social care has fallen by 12 per cent at a time when the number of those looking for support has increased by 14 per cent. This has forced departments to make savings of 26 per cent in their budgets – the equivalent of £3.53 billion over the last four years’, ADASS 2014: <http://www.adass.org.uk/social-care-services-unsustainable-adass/> Also Fernandez, J-L et al, Changes in the Patterns of Social Care Provision in England: 2005/6 to 2012/13, PSRRU, Kent/LSE, 2013, concluded that ‘453,000 fewer people received social care in 2012-13 than would have done in 2005-06’. For children see <http://www.independent.co.uk/news/uk/home-news/social-work-budget-cuts-are-putting-children-at-risk-says-nspcc-9224796.html>

<sup>40</sup> For example see: <http://www.independent.co.uk/life-style/health-and-families/health-news/cuts-leave-nhs-mental-health-services-dangerously-close-to-collapse-9667370.html>

<sup>41</sup> See: <http://www.communitycare.co.uk/2014/04/09/deeper-cuts-adult-social-care-packages-planned-council-budgets-drop-4/>

<sup>42</sup> Beatty, C and Fothergill, S, ‘Hitting the Poorest Places Hardest’, Sheffield Hallam University, 2013. Financial losses are calculated to be £4.3 bn a year from incapacity benefits; £3.6 bn a year from tax credits; £3.4 bn a year from limited uprating of benefits; and £450m a year from the ‘bedroom tax’. See:

[http://www.shu.ac.uk/research/cresr/sites/shu.ac.uk/files/hitting-poorest-places-hardest\\_0.pdf](http://www.shu.ac.uk/research/cresr/sites/shu.ac.uk/files/hitting-poorest-places-hardest_0.pdf)

<sup>43</sup> ‘The Human Cost’, Shelter, 2010. See:

[http://england.shelter.org.uk/\\_data/assets/pdf\\_file/0003/268752/The\\_Human\\_Cost.pdf](http://england.shelter.org.uk/_data/assets/pdf_file/0003/268752/The_Human_Cost.pdf)

<sup>44</sup> According to Navca, following a survey of its members, 2013. See: <http://www.thirdsector.co.uk/local-infrastructure-groups-pessimistic-future-navca-survey-reveals/infrastructure/article/1194289>

- Voluntary and community groups have lost local authority grants, and have little influence or visibility in the new health commissioning arrangements.<sup>45</sup>

The spending restraint in health and social care has also exacerbated the degree to which services work in reactive, crisis-driven, inefficient ways that make it very difficult to plan for the more proactive, preventive, coordinated models of care everyone wants to see.

Over time, the changes called for in this document will enable prevention, early intervention and support for independence and wellbeing better to offset the demand for expensive, emergency interventions.

Such an ambitious and necessary transformation, however, needs a secure funding base to succeed. It will also need real term increases in health and care funding in the medium and longer term: transformation cannot be achieved without the funds to change services.

National Voices calls on the next government to support a well-funded health and care sector with a **guaranteed five year** financial settlement. We think that key elements of such a settlement must include:

- Real terms increases in health funding adequate to maintain the core principle of predominantly **free use** of the NHS according to need. The UK committed to doing this in 1948 in the midst of post-war austerity and should reaffirm this commitment as a much richer country coming out of recession
- Real terms increases for social care funding, sufficient to deliver on the policy goals of the **Care Act 2014**. In particular that means that **funded social care** should be available for larger numbers of adults with assessed needs; social care should be available **free** for people needing end of life care<sup>46</sup>; and there must be adequate funding to support **children with disabilities**. It must also remain possible for local authorities to fund open access services that help maintain people's health and wellbeing
- Clear movement towards local/sub-regional **single place budgets** for health and social care, as areas become ready.
- **Transformation** funds, nationally provided but locally delegated according to agreed goals and criteria, to enable the shift towards person centred coordinated care.

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<sup>45</sup> Bhati, N and Heywood, J, 'Counting the Cuts', National Council for Voluntary organisations, 2013. NCVO estimates that funding for voluntary sector will be £1.7 billion lower by 2017/18 than it was in 2010/11 (using 2010/11 prices). See: [http://www.ncvo.org.uk/images/documents/policy\\_and\\_research/funding/counting\\_the\\_cuts\\_2013.pdf](http://www.ncvo.org.uk/images/documents/policy_and_research/funding/counting_the_cuts_2013.pdf)

<sup>46</sup> 'There's no place like home', Macmillan, 2013. See: <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/SocialCare/Making-the-case-for-free-social-care-at-the-end-of-life.pdf> and Johnston, L et al, 'How could free social care at the end of life work in practice', Office for Public Management, 2014: <http://www.opm.co.uk/publications/how-could-free-social-care-at-end-of-life-work-in-practice-3/>

- A **growth fund** for voluntary and community sector infrastructure to support an increasing role for the sector in health and wellbeing
- **No further extension of charging** for health and care services, since this undermines the principle of services delivered according to need rather than ability to pay, and reinforces health inequalities.

## Appendix: National Voices' work to support person centred care

National Voices is the national coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We are a charity and a company limited by guarantee.

We have about 160 members with 140 charity members and 20 professional and associate members. Our broad membership covers a diverse range of organisations, health conditions and communities and connects with the experiences of millions of people. Since our inception in 2008 National Voices has been at the centre of efforts to promote person-centred care:

**The NHS Constitution.** We have helped various review and advisory groups to review and improve the [Constitution](#). We want to see its values and principles upheld throughout the NHS, and the rights and pledges it contains become a reality.

**The Narrative for person centred coordinated care** – coproduced with service users and their organisations, and written from the perspective of people needing care over time from multiple services, this [Narrative](#) is the nationally adopted definition for what 'integration' should be designed to achieve.

**Additional narratives for coordinated care.** We have gone on to describe how coordinated care would look from the point of view of older people with a long term condition; people who use mental health services; and people in the last 12 months of life.

**Care and support planning policy.** We worked throughout the passage of the Care Act 2014 to ensure that the legislation and guidance support best practice in personalised care planning, and enable this to be integrated across health and social care.

**The care and support planning guide.** This [guide](#) is designed to help people and their professionals use personalised care and support planning as the delivery mechanism for person centred care. It is fully up to date with current legislation and policy, and is referenced as a standard by the Department of Health, NHS England, Health Education England, and the national guidance for the Care Act 2014.

**Patient participation policy.** We successfully campaigned for a clear statutory duty for healthcare commissioners, in all that they do, to promote the involvement of patients in decisions; and we helped NHS England draw up [guidance](#) to CCGs on ways to fulfil that duty.

**Evidence for the achievement of patient involvement.** We published the most comprehensive [review](#) available of the research evidence on what interventions are effective to support people to take control of decisions and actions in relation to their health, care and support.

**Building the House of Care.** We are founder members of the [Coalition](#) for Collaborative Care which promotes the development and spread of the House of Care approach to better support people with long term conditions. The coalition unites statutory and non-statutory stakeholders from health and social care around personalised care and support planning. We helped shape relevant content at the Future of Health Conference and NHS Expo to disseminate the approach.