National Voices

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National Voices' submission to the consultation on Improving lives: the work, health and disability Green Paper

February 2017

About National Voices

National Voices is the coalition of health and social care charities in England. We work for a strong patient and citizen voice and services built around people. We stand up for voluntary organisations and their vital work for people's health and care.

We have more than 140 charity members and 20 professional and associate members. Our membership covers a diverse range of conditions and communities, and connects with the experiences of millions of people.

National Voices has been a member of the Department of Health's Health and Care Strategic Partner Programme since 2011. The programme brings the power of the voluntary sector together with the health and care system, to improve services and promote wellbeing for all.

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Introduction

National Voices is pleased to have the opportunity to respond to the consultation on the new Green Paper on work, health and disability.

We welcome the Government's commitment to support people with long term conditions and disabilities to stay in, return, or start work where this will benefit their health and wellbeing. There is a positive emphasis throughout the Green Paper on taking a personalised or person-centred approach to both health and employment support, and to better joint working across Government.

In this response, we will focus on a number of concerns that we, and our members, have about what is set out in the Green Paper. We have focused in particular on the chapter on health, providing some reflections and recommendations that fall outside the questions asked, but which are critical to ensuring that support is effective. We also highlight some cross-cutting issues shared by many of our members relating to the rest of the paper.

In summary:

Section 1: Supporting employment through health and high quality care for all

1. **A person-centred approach to supporting people with long term conditions and disabilities to work is welcome. However, the Green Paper underestimates the personal, and organisational barriers to achieving this. It also does not question whether existing employment support should be redesigned.**
2. **Care and support planning consultations *may* offer people the opportunity to discuss their work goals and their corresponding support needs. They will only be effective where people are able to identify their own support needs. Care and support planning is not yet routinely offered in health settings.**
3. **Work is not an appropriate health outcome for everyone. Clinicians must be able to discuss the impact of health on work and vice versa, but the person's health needs must always be primary.**
4. **Data sharing can help improve coordination of support. However, this poses practical challenges given different information systems. Health and care data should only be shared with employment services with the person's explicit and informed consent.**
5. **The welcome emphasis on preventing people getting ill is not reflected by investment in public health and prevention. Cuts to services will lead to avoidable ill health and use of health services, and to unemployment. It undermines the Five Year Forward View.**

Section 2: Working in partnership with the voluntary sector

6. **National Voices welcomes the recognition of the many roles that the voluntary sector can play in supporting health, care and employment. However, the sector has experienced significant funding cuts, and cannot be used as a free resource by the statutory sector.**
7. **The voluntary sector should be seen as a partner, working in coproduction to design and deliver not only services, but mechanisms for working with the sector**
8. **Each local area will have a unique set of voluntary services available. Jobcentres should seek to coordinate with existing processes to map this rather than duplicate efforts.**
9. **Person centred employment support that meets people's real needs, values and preferences would be coproduced to design tailored local solutions.**
10. **Volunteering is an important alternative to paid employment, and can improve health outcomes as well as supporting people back into a job. Work coaches should be able to advise on local, high quality volunteering opportunities.**

Section 3: Understanding the barriers to work faced by people with long term conditions and disabilities

11. **Research is needed to understand why more people in the Support Group are not currently able to work; solutions should be evidence based.**
12. **The Green Paper underplays many of the often significant barriers to work faced by people with long term conditions and disabilities. Fluctuating and progressing conditions, and stigma or discrimination due to either visible or invisible conditions, may affect an individual's ability to work.**

Section 1: Supporting employment through health and high quality care for all

1. **A person-centred approach to supporting people with long term conditions and disabilities to work is welcome. However, the Green Paper underestimates the personal, and organisational barriers to achieving this. It also does not question whether existing employment support should be redesigned**

It is increasingly recognised that being able to work – or, perhaps more broadly, being able to take part in meaningful activities – confers health benefits for people. In the health sector, there is increasing discussion of 'work as a health outcome'.

It is therefore welcome that this Green Paper focuses on helping people to stay well enough to remain in or return to work, as well as recognising the importance of closer working between different statutory organisations that people work with. We are pleased to see reference to our work on the Five Year Forward View.

National Voices in general welcomes the ambition to adopt a person-centred approach to employment support. People are experts in their own conditions, circumstances and lives. Working with them in partnership to understand their motivations, their hopes, their preferences and the impact that their health condition(s) have on them, will help identify the most appropriate support for that individual.

However, the Green Paper too often assumes a mechanistic effect: for instance, that consultations with work coaches will lead to employment placement. Experience from health and healthcare suggests that this significantly underestimates the barriers in the way of self-efficacy.

National Voices would particularly highlight two types of barrier: personal and organisational.

Personal barriers

In the realm of health and healthcare it is now well recognised, including in the NHS' Five Year Forward View document, that an essential foundation for future healthcare

is to support people to manage successfully with continuing ('long term' or 'chronic') conditions. But it is also evidenced that simply providing people with more or better information, or with consultations with professionals, does not in itself increase people's capacity for self-management.

The majority of people with long term conditions also have relatively low health literacy (meaning the capacity to make use of information for decisions relating to their health). If the aim is to help people change their behaviour and manage more successfully, then additional action is necessary, focused in particular on building their 'knowledge, skills and confidence' to manage.

In working to build people's confidence, evidence shows that proceeding via 'baby steps' is advisable. Where professionals ask someone with low health literacy and confidence immediately to address their greatest health challenges (such as an addiction) success is likely to be low. But where people can experience success in achieving less onerous change (such as walking to the shops instead of taking the bus, to increase exercise), this contributes to growing confidence to take on bigger changes.

This needs to be similarly recognised with regard to the world of work. Many people with continuing conditions have personal limitations that they feel prevent them from taking full time employment. Their confidence to take on work can be built over time through smaller steps, such as volunteering, taking social action, getting work experience, taking part time work; together with other inputs such as relevant training, coaching and supervision. The Green Paper says little about this stepwise approach and in particular is remarkably silent on the role of volunteering, both as a valuable contributor to the health and wellbeing of the volunteer, and as a potential pathway towards paid work.

Organisational barriers

With regard to organisational barriers, our experience from health is that making support more person-centred is not always an easy task. It requires a significant shift in culture for many practitioners, particularly in organisations that are historically paternalistic or transactional. Person centred services are based on the quality of relationships, and often require a change in attitudes and behaviours on the part of staff, as well as service users. These services prioritise the needs and interests of the individuals, not the institution.

This is an ongoing process of change within health, and requires training and support for staff to change attitudes or behaviours based on traditional education, training and professional modelling.

Various approaches to supporting this change have proven successful in health, for example communities of practice, networks, champions etc. Adopting a person-centred approach to employment support will be beneficial to service users and

potentially staff; however, if it is to be successful it cannot simply be a box ticking exercise, it will take effort to change the culture.

Redesigning services and support

The Green Paper is also mechanistic in assuming that the existing system of assessments, coaching and advisory functions only needs tweaking to become more efficient. There appears to be no room in the discussion to question whether these support services need to be redesigned. Ideally there should be more place for locally tailored solutions, developed in coproduction with the service users.

2. **Care and support planning consultations *may* offer people the opportunity to discuss their work goals and their corresponding support needs. They will only be effective where people are able to identify their own support needs. Care and support planning is not yet routinely offered in health settings.**

We are pleased that the Green Paper recognises the potential for care and support planning in health and care. This is something for which National Voices has long advocated, having heard the evidence from people who are managing long term conditions.

However, the government must not overestimate the extent to which this is routinely happening. In health, in particular, care and support planning is far from routine. The vast majority of people with long term conditions do not have the opportunity to engage in planning their care. Only around 5% say they have a care plan in which they participated.

Thus there is no 'ready made' system into which elements of work-related coaching or planning can be built.

Care and support planning consultations, where they are offered, involve people in identifying what matters most to them, setting goals for their health and wellbeing, and deciding how they want to be supported to achieve these.

It may well be that these goals, and support packages, have elements that help people to stay in or to move into work or other meaningful activities. To be effective, however, care and support planning in either health or social care must be directed by the person with needs, with no 'requirement' to discuss work. As Section 10 of the government's statutory guidance to the Care Act 2014 expresses it:

> "the guiding principle in the development of the plan is that this process should be person-centred and person-led, in order to meet the needs and achieve the outcomes of the person in ways that work best for them as an individual or as part of a family. Both the process and the outcomes should be built holistically around people's wishes and feelings, their needs, values and aspirations"

Where work (or other meaningful activities) are part of a goal that is personally identified during these sessions, it is important that clinicians have access to information about (and ideally the ability to refer the person to) specialist employment support or similar services that will help people take steps towards their goal.

A formal mechanism such as social prescribing should be in place to link people to community support services that will help people reach their identified goals.

Community support that can help people meet their goals could include, for example, peer support, health education courses, exercise groups, information and advice, advocacy. Many of these approaches offer help to improve not only health outcomes but also confidence, motivation and knowledge – these could therefore help support people to stay in or return to work.

The menu of options should also include employment support. There may be some benefit in considering at a local level how social prescribing could relate to formal and community employment support.

This model must be underpinned by a commissioning approach which recognises the need for care and support planning, and which values investment in community support to ensure that there are services in the community to which people can be referred. Local healthcare commissioners, however, in general have little experience or know-how with regard to community asset development.

3. **Work is not an appropriate health outcome for everyone. Clinicians must be able to discuss the impact of health on work and vice versa, but their health needs must always be primary.**

More generally, care must be taken when health staff raise the subject of work with patients. While this may be beneficial in identifying the most appropriate treatment and support for an individual, care must be taken to ensure that the primary focus of health consultations remains the health of the individual: this should be the priority. It would be completely inappropriate if patients were pushed towards or compelled to undertake a particular course of treatment on the basis that it would increase their employment prospects.

The Green Paper includes the idea of work as a health outcome. This will not be appropriate for all patients, for example those with rapidly progressing and terminal diseases such as Motor Neurone Disease; or with fluctuating conditions that include periods of severe disabling symptoms. While people with these conditions may want to remain in work, this may not be achievable, and would therefore be an inappropriate outcome for them.

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4. **Data sharing can help improve coordination of support. However, this poses practical challenges given different information systems. Health and care data should only be shared with employment services with the person's explicit and informed consent.**

While we recognise the potential benefits of data sharing between the various agencies that an individual works with, to ensure more coordinated support and reduce the need to repeat details about their conditions and lives, we urge caution regarding the proposal to share health data with Jobcentre Plus.

First, this presents a practical challenge that it is not clear local services are able to meet. The governance of information sharing, the creation of interoperable records, the matching of software systems, and the creation of adequate consent mechanisms, all remain highly problematic within healthcare, and across health and social care; let alone introducing a new service.

Second, there is a risk that some people in receipt of benefits will be discouraged from speaking to their GP if they fear that what they say will be reported to the people that make decisions about their income. Any sharing of data would need to be done on the basis of explicit consent, and the mechanisms for this should be designed in coproduction with people with lived experience of both long term conditions and disabilities, and of benefit receipt. If this is done in a way that undermines trust in health and care professionals, it will pose a real risk to the health of the very people the proposal is meant to protect.

5. **The welcome emphasis on preventing people getting ill is not reflected by investment in public health and prevention. Cuts to services will lead to avoidable ill health and use of health services, and to unemployment. This undermines the Five Year Forward View.**

The Green Paper emphasises the importance of promoting health and preventing ill health. We agree that these are key, and applaud programmes such as the Diabetes Prevention Programme, still in its early stages, but which was co-designed with people with lived experience.

The emphasis on prevention is not reflected in funding. Spending on public health was cut by £200 million mid-year in 2014-15, and the 2015 Autumn Statement introduced cuts of an average of 3.9 per cent per year until 2020-21. This is having a detrimental effect on frontline services, including NHS sexual health care and smoking cessation. These cuts undermine the Government's commitment to the Five Year Forward View which prioritises preventative work to ease pressure on health services, and which relies on appropriate funding for public health to improve sustainability of health and care.

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Section 2: Working in partnership with the voluntary sector

6. National Voices welcomes the recognition of the many roles that the voluntary sector can play in supporting health, care and employment. However, the sector has experienced significant funding cuts, and cannot be used as a free resource by the statutory sector.

We are pleased that the important role that the voluntary, community and social enterprise (VCSE) sector plays in supporting people with long term conditions and disabilities is recognised throughout the Green Paper.

The VCSE sector provides direct support to people with long term conditions and disabilities, including information about conditions, self-management education, advocacy and peer support, and support to get back into work, including volunteering.

It holds expertise on the experiences of the people it supports, often those with particular conditions or backgrounds, including those from seldom-heard groups such as people who are homeless. VCSE organisations can help statutory services work with people with lived experience to improve services. They can work in partnership at a local and national level to shape policy, develop evidence and research, and design services.

We firmly believe that the voluntary sector has a vital role to play in promoting health and wellbeing, and in improving support for people to stay in work. It has unique strengths that the statutory sector should continue to embrace in partnership.

The voluntary sector has not been spared austerity. At local level in particular there has been a huge reduction in grants as a consequence of shrinking local authority funding. Commissioning carried out through competitive tendering has excluded or disadvantaged many smaller organisations. Infrastructure bodies have shrunk, and in some areas disappeared. This has weakened the sector, led to changes in the services provided, and left many organisations in a precarious situation.

Voluntary services must not be seen as a free or cheap resource to supplement a shrinking public sector. Investment in the voluntary sector is essential if the full benefits of partnership working are to be realised.

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7. **The voluntary sector should be seen as a partner, working in coproduction to design and deliver not only services, but mechanisms for working with the sector**

For the formal sector to be able to make the most of this potential, it needs to get far better at three things:

- Working in coproduction to build trusted relationships;
- Creating funded, open, fair and mutually beneficial partnership opportunities at a range of levels;
- Understanding the importance of voluntary sector 'infrastructure', and the organisations that provide it, as trusted brokers for the inclusive involvement of the sector as a whole.

This ground has been very well covered by the final report of the VCSE Review[1] and by the Realising the Value programme[2].

Working with the voluntary sector to design not only the support provided but the mechanisms for working with the voluntary sector will help ensure that partnership working is most effective. This would mean, for example, working with the voluntary sector (and others) to ensure that the process used for the new Dynamic Purchasing System is accessible to voluntary sector organisations who often find public sector contracting too burdensome. Grant funding is more appropriate, particularly when working with small VCSE organisations.

We are pleased that the Government is "committed to building a pipeline of innovation to rapidly improve support to individuals". We would urge consideration of how this can be designed to ensure that the voluntary sector can fully engage and contribute.

8. **Each local area will have a unique set of voluntary services available. Jobcentres should seek to coordinate with existing processes to map this rather than duplicate efforts.**

We welcome the proposal to ensure that a map of local services, including peer support and patient groups, is available within Jobcentres, which can be used to signpost people and identify gaps in provision. However, similar mapping work will already be underway in most localities, looking at the voluntary sector more broadly. For example, the local Joint Strategic Needs Assessment may include an asset map; the local authority may have a database of community sector assets; the CCG may

[1] Commissioned in 2014 by the Department of Health (DH), Public Health England (PHE), and NHS England to review of the role of the VCSE sector in improving health, wellbeing and care outcomes.

[2] A programme set up by NHS England and led by NESTA and the Health Foundation to strengthen the case for the change set out in the Five Year Forward View; identify evidence-based approaches that engage people in their own health and care; and develop practical tools to support implementation across the NHS and local communities.

have a map of organisations working to support health and wellbeing. Efforts should be made to avoid unnecessary duplication, and identify ways to develop joint mapping, or if not, coordinate these efforts to be able to point people towards a holistic range of support services.

The consultation asks which specialist tools should be provided to work with disabled people and those with long term conditions. There is a wide range provided by our members, which they will be sharing with you. However, it would be impossible to provide a definitive list of tools, given the wide range of conditions, voluntary sector organisations, and the evolving nature of this work.

It is therefore vital that, as well as collating a set of tools for more common conditions, Work Coaches are trained to understand the local and national VCSE sector, and are equipped to help people identify patient organisations who will be able to provide information or support.

9. **Person centred employment support that meets people's real needs, values and preferences would be coproduced to design tailored local solutions.**

People with long term conditions and disabilities are experts on their conditions, on the experience of being unwell, on how to manage their health and care, and of the barriers they face in day to day life, including work. National Voices advocates that health and care services are designed in (equal) partnership with people who use services, and with the general public where appropriate.

We believe that the principle of coproduction should underpin efforts to improve employment support, and coordination of this with health and care. While there are different forms of coproduction, in this sense we mean people and communities on the one hand, and employment, health and care professionals and services on the other – working together as equals, from the start of a project or programme, with equal influence and decision power on designing and implementing that project.

The Green Paper is again too mechanistic, basing its proposals on expanding, or making better use of, the existing mechanisms created by government, especially the coaches and advisers. For employment support to be responsive to people's real needs, values and preferences, there should be room to invest in coproduced and tailored local solutions.

10. **Volunteering is an important alternative to paid employment, and can improve health outcomes as well as supporting people back into a job. Work coaches should be able to advise on local, high quality volunteering opportunities.**

As noted above, the role of volunteering in work, health and Volunteering can be beneficial to those who struggle to find work as a result of barriers related to their condition, to employer attitudes, or the local economy. It can offer an alternative route to employment that accrues health and wellbeing outcomes in its own right.

Volunteering reduces social isolation, helps put people in touch with opportunities in their local community, helps them to develop new skills and demonstrate experience, and may be more accommodating of fluctuating ill health. Work coaches and others providing work support should be able to advise on good quality local volunteering opportunities[3] and help people not ready or able to work to volunteer their time and skills.

Section 3: Understanding the barriers to work faced by people with long term conditions and disabilities

11. Research is needed to understand why more people in the Support Group are not currently able to work; solutions should be evidence based.

Underpinning much of the Green Paper is an assumption that a key barrier to work is 'attitude'; that the proportion of people in the Support Group reflects a lack of belief that they can or should work. This is a sweeping generalisation, and patronises people with health conditions.

This emphasis on the attitude to work among people disability and long term conditions does not appear to be based in evidence, and ignores the experience of those who enter work with long term conditions or disabilities, or who have developed these after years in work. There may be real issues about providing support and building up confidence (or changing skills) – this is not necessarily about an 'attitude' to work. Many of those who will need support to work will desperately want to work and be frustrated they can't, or scared they will lose their jobs as a result of their condition.

Further to this there does not appear from the Green Paper to have been sufficient work done with this group to understand the barriers they face – many voluntary sector organisations have done this type of analysis for the conditions they specialise in.[4] Without a better understanding of why people in this group are not in work, the help that would benefit them most, and an evidenced baseline for the proportion in the Support Group who could be in work.

12. The Green Paper does underplays many of the often significant barriers to work faced by people with long term conditions and disabilities. Fluctuating and progressing conditions, and stigma or discrimination due to either visible or invisible conditions, may affect an individual's ability to work.

While National Voices fully recognises the benefits to health and wellbeing that often accrue from paid employment, we are concerned that the Green Paper underplays

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[3] Good quality here would include that the volunteering service is well led; adaptable to people's needs and disabilities; and provides training and development as part of the experience.

[4] See for example: http://www.arthritisresearchuk.org/policy-and-public-affairs/reports-and-resources/reports/work-report.aspx

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the significant barriers to work that many people with long term conditions and disabilities face.

Many of these barriers will be health related. There is a lack of recognition in the paper that some people will face rapidly deteriorating, or terminal conditions that mean that it will not be possible to stay or re-enter work. In these circumstances, proposals around regular discussions with work coaches for those in the Employment and Support alliance (ESA) support group would not be appropriate, and may cause avoidable distress.

Other people may have conditions which are made worse by work, for example some people with muscular-skeletal conditions, and those with MS. Additional barriers will be faced by people whose condition fluctuates over time: while they may be able to work for periods, they may frequently find that their condition means that they can't work. This will be difficult for both them and their employer to manage, leaving them unable to work. There is little support available for people in this situation, and given the presenteeism within many organisations can make it difficult to remain in post.

Stigma and discrimination

People with invisible conditions such as migraines may find it difficult even where they disclose to get the proper support from employers who struggle to understand the real physical challenges of their conditions and the impact this has on them.

Conversely, our member Changing Faces, which supports people with disfigurements to live the life they want, highlights the barriers that people with disfigurements face gaining work and promotion due to the unconscious (and conscious) bias of employers and recruitment panels. This bias will affect other people with visible disabilities or long term conditions, and may be difficult to overcome.

The proposals for challenging stigma in the Green Paper place the onus for change on the person with the disability, and implicitly assumes that the problem is mainly one of non-disclosure. Overall the proposals relating to employers are light touch. They do not adequately address the impact on employers of supporting people with long term conditions; nor do they offer employment protection to people with long term conditions or disabilities who do not receive the support they need to stay in work and are forced out.