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# Co-production, collaboration and consultation: the shared experiences of a third sector organisation and researchers in the North East of England

Andrew Clifton and colleagues outline how a collaborative research project involving the third sector has been established to examine the impact of welfare reforms on service users

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## Abstract

A research project in the North East of England investigating the impact of welfare reform on people with mental health problems has been established through a collaboration between mental health nurses, third sector workers and researchers. Partnerships involving the third sector are likely to become more common for mental health nurses.

## Key words

Third sector, research, welfare reform, collaboration

## Reference

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## Introduction

The emergence of the 'third sector' in the 1990s was a policy response by the New Labour government to address issues of social exclusion and economic inequality that emerged as a result of individualistic and free market policies implemented by previous governments (Fyfe, 2005).

During this period there was a shift towards 'community care', in which a number of third sector mental health organisations were established – with many of these groups, charities and associations providing services, campaigning and advocating on behalf of mental health service users.

An increasing emphasis on community care and the use of evidence-based treatments (including talking therapies) has created opportunities and empowered many service users to facilitate their own recovery.

The ever-increasing marketisation of health and social care (often resulting in a streamlining of services), state-sanctioned austerity measures and recent changes to the welfare system have left many mental health service users vulnerable, socially isolated and bereft of the financial means to lead independent lives.

NHS mental health services are stretched to the limit and often service users are merely 'managed' or 'maintained' and locked into a system that is risk-averse and economically inefficient (*The Independent*, 2013).

Service users remain frustrated and often

angry with a system propagating 'social control' rather than recovery, with many turning to third sector organisations that can offer the practical and emotional support many people require, although it is important to emphasise that the NHS, private and third sector organisations all have a role to play in facilitating recovery for service users in the current climate.

Indeed, mental health nurses are the largest professional group of workers (Clifton et al, 2012) providing support and care for people experiencing mental health problems, therefore it is vitally important that they and other practitioners engage with a range of public, private and third-sector stakeholders to support the needs of mental health service users.

The purpose of this article is to discuss the collaborative process between a third sector organisation and a team of researchers from Northumbria University who recently completed a consultation examining the impact of the coalition government's reforms to the welfare system.

Practitioners including mental health nurses, researchers and volunteers increasingly work with service users in a range of contexts including clinical practice, research and raising the profile of mental health issues.

This consultation was completed in a spirit of co-production and the following discussion outlines the nature of the collaboration, considers a range of ethical issues and discusses both the benefits and challenges of such ventures.

### **The development of the North Tyneside Mental Health Forum**

The North Tyneside Mental Health Forum was established in 2010 by a mental health user development worker, Jane Noble, as a response to service users who wanted somewhere they could attend for information and advice, and the opportunity to engage with other service users.

This need was identified over a period of eight months, which was necessary to network, meet service users and listen to what opportunities they would require.

The early forum meetings offered largely 'peer support', advice and information. However, as the forum developed service users wanted to invite keynote speakers such as welfare rights advisers, who could explain any relevant changes to provision and provide a platform for further discussion.

Now the forum is well established, it has also become a vehicle for the development worker to advocate on behalf of service users when developing new strategies and/or services with the local primary care trust.

### **The changing provision of welfare**

One of the most salient issues concerning service users who attend North Tyneside Mental Health Forum is the current changes to welfare provision in the UK initiated by the coalition government in 2010.

One of the least-reported aspects of the changes is that some households and individuals, notably sickness and disability claimants (including those with a mental health difficulty) will be hit by several different elements of the reforms (Scottish Parliament, 2013) (see Box 1).

There has been an increase in the number of people claiming sickness-related benefit in the last 30 years (Barnes et al, 2010), with 2.63 million currently receiving Incapacity Benefit (Lewis et al, 2013). This includes some mental health service users who are often subject to changes in disability policy and administrative procedures (Cook and Jonikas, 2002) such as the Welfare Reform Act (2007).

There is evidence to suggest that up to 35% of all disability benefits in some countries are accounted for by mental health problems (Harvey et al 2009).

This reform was planned in a relatively buoyant economy, meaning there is added significance to the changes, caused by the deep economic recession (Sissons, 2009).

The coalition government is looking to reassess all those on Incapacity Benefit. Both Incapacity Benefit and Income Support based on incapacity will migrate to Employment and Support Allowance (ESA). This is part of a broader set of reforms introduced to move from a passive to an active welfare system, and as a response to the green paper *A new deal for welfare: Empowering people to work* (Department of Work and Pensions, 2006).

The 'migration' of service users from original benefits to the new ESA is intended to continue until 2014/2015 (Callanan, 2011; Sissons, 2009). ESA claimants are more likely to be male, live in social housing and be a single or lone parent, and compared to the UK population they are an economically disadvantaged group (Barnes et al, 2011).

Though there is little understanding of the direction of causality, studies have shown that those with longstanding mental health problems are more likely to become unemployed or never gain employment, and that individuals who are out of work have a higher rate of common mental disorders (Ford et al, 2010).

Initial application for ESA is by the ESA50 questionnaire, which is longer and more complex than its predecessor, making the process more difficult for claimants with learning disabilities or mental health problems (Roxburgh, 2011). Some people have said they struggled with the form, and had little information in the lead-up (Barnes et al 2010). This is supported by other studies, which also highlight how there will be increasing demand for advice and advocacy from already overstretched services (Barnes et al, 2010; 2011; Roxburgh, 2011), a theme throughout the existing literature being that of an information deficit (Barnes et al, 2010).

However, the process in full is supposed to be faster, and has a focus on what claimants can do, rather than what they cannot (Barnes et al, 2011).

### **Establishing the collaboration**

The service users of North Tyneside Mental Health Forum requested that Jane Noble, their representative, facilitated a consultation to formally capture their experiences of the recent changes to welfare provision.

Jane requested collaboration with the author of this proposal, Andrew Clifton, to mentor the development of the consultation design, lead the consultation activity and provide the final report in his capacity as an experienced

researcher and practitioner in mental health nursing.

The third member of the consultation team, Jennifer Remnant, was an honorary researcher at Northumbria University who has supported the development of the consultation design and will support Andrew in the analysis and dissemination of the findings.

The final member of the team, Joanna Reynolds, was invited to collaborate on the project to provide expertise and advice on any ethical issues that may arise as a result of the collaboration. The work added to previous collaborations and existing links between the trust and Northumbria University.

### **Ethical issues**

This consultation supported service development on both a micro and macro level by responding to service user-needs (i.e. their wish to capture their experiences of welfare reform), and sharing these experiences with the PCT. This ensures that any current or future service development within the PCT will be conducted with an awareness of the social impacts that also shape the service user experience.

The consultation used research methods with participants, therefore there were a number of ethical considerations to address, particularly in light of the fact that universities and NHS research and development departments consider mental health service users to be vulnerable when participating in research and development activity.

Responding to service users' requests for a consultation placed Jane, their representative within the Forum, as an 'insider' facilitator of the consultation activity. To address the potential issues of bias, power dynamics or coercion, Jane initiated the collaboration with Andrew and his research team.

The collaboration ensured shared facilitation of the consultation methods; Jane coordinated the questionnaire phase and Andrew led the focus groups. Andrew is experienced in conducting focus groups with service users and since he is removed from the consultation context he provided a neutral facilitation role.

### **Informed consent**

Voluntary participation is at the heart of ethical practice in research and development activity, supported through the process of informed consent (World Medical Association, 2008; Department of Health, 2005).

Ensuring voluntary participation, particularly

with service users within 'insider facilitated' activity, and with participants defined as vulnerable, presents key challenges. Service users can feel obligated to participate, or can make their decision through fear of loss or change to their service provision if they choose not to take part. In this case the service users are a well-formed group who have been meeting for a number of years.

The group emphasised that they would be quite comfortable in saying no to participating in any aspect of the consultation activity, but clarified that they had requested the consultation and were all keen to take part.

Full, detailed information on both phases of the consultation was provided. A verbal information session was conducted during one of the scheduled Forum meetings, accompanied with written information leaflets which were distributed to all service users.

Potential participants were clear from this information that they were not obliged to take

part and there would be no adverse outcomes or impacts on their service provision if they chose not to participate. They were clear that they could choose to take part in one or both of the study phases (i.e. questionnaire and/or focus group), and were free to withdraw from the study at any time without giving a reason.

Returning the questionnaire was taken as participants' consent to take part in the questionnaire phase of the consultation, as is typical practice. Consent forms were completed at the start of the focus groups, once participants' questions had been answered.

#### **Provision to support participants' distress**

Since the consultation was exploring service users' experiences and perspectives of changes in welfare provision, there was the potential for participants to become distressed.

Service users completed the questionnaires independently during a scheduled Forum

meeting, with their representative (Jane) present, who was able to provide support during the meeting and beyond where necessary. The focus groups were conducted by Andrew, who is a mental health practitioner experienced in conducting research and evaluation with service users.

While focus groups were being conducted, Jane was available on site to offer support for any participants who became distressed and wished to leave the focus group. Information was available for participants about other service provision to help with signposting where necessary (e.g. welfare agency and mental health charities).

#### **Anonymity and confidentiality**

The service users requested the consultation in order to formally capture their experiences of the changes to welfare provision. They were aware they would be asked questions about their experiences in the questionnaire, and that they would discuss personal information in front of each other in the focus groups.

The information leaflet emphasised the lack of anonymity for participants within a focus group, and the boundaries of confidentiality within the consultation. If participants disclosed information relating to harm to themselves or to someone else, they were aware that this information may need to be shared by Andrew with either the service user representative and/or with relevant services.

#### **Outputs and dissemination**

All participants will receive a summary report of the findings, with the opportunity to read the full report and/or discuss the findings via the Forum meetings. Jane will work with the service users via their Forum meetings to agree on the best ways in which to share the findings with the trust and other interested stakeholders.

#### **Benefits and challenges of the collaboration**

Arguably one of the main benefits of this collaboration and resulting consultation was the platform and space provided for service users to give their views and opinions on how recent welfare reforms have impacted on their individual lives, with the results due to be reported around the middle of 2013.

The co-production of this consultation was a significant feature of the collaboration with service user involvement evident at all stages of the consultation process. Importantly, the

### **Box 1. Summary of welfare reforms**

#### **Housing Benefit – Local Housing Allowance**

Changes to the rules governing assistance with the cost of housing for low income households in the private rented sector. The new rules apply to rent levels, 'excess' payments, property size, age limits for sole occupancy, and indexation for inflation.

#### **Housing Benefit – Under-occupation**

Changes to the rules governing the size of properties for which payments are made to working age claimants in the social rented sector (widely known as the 'bedroom tax')

#### **Non-dependant deductions**

Increases in the deductions from Housing Benefit, Council Tax Benefit and other income-based benefits to reflect the contribution that non-dependant household members are expected to make towards the household's housing costs

#### **Household benefit cap**

New ceiling on total payments per household, applying to the sum of a wide range of benefits for working age claimants

#### **Disability Living Allowance**

Replacement of DLA by Personal Independence Payments (PIP), including more stringent and frequent medical tests, as the basis for financial support to help offset the additional costs faced by individuals with disabilities

#### **Incapacity benefits**

Replacement of Incapacity Benefit and related benefits by Employment and Support Allowance (ESA), with more stringent medical tests, greater conditionality and time-limiting of non-means tested entitlement for all but the most severely ill or disabled

#### **Child Benefit**

Three-year freeze, and withdrawal of benefit from households including a higher earner

#### **Tax Credits**

Reductions in payment rates and eligibility for Child Tax Credit and Working Families Tax Credit, paid to lower and middle income households

#### **1 per cent up-rating**

Reduction in annual up-rating of value of most working-age benefits

Source: (Scottish Parliament, 2013).

focus of the consultation was driven by service users who also contributed to the development of the content of the questionnaire. Therefore, the 'authentic' voice of the service user was captured within the design of the data collection methods.

The consultation was co-produced in a spirit of partnership working while maintaining ethical standards around issues of informed consent, confidentiality and providing support for service users experiencing distress or emotional discomfort as a result of the consultation process.

A particular facet of this collaboration was the way in which service users supported the researchers on numerous occasions, including the generation of more participants (on a freezing January afternoon) and by creating a relaxed, supportive and friendly environment in which to conduct the focus groups.

Finally, the collaboration provided the researchers an opportunity to work with a third sector organisation and to experience first hand the support and valuable work such organisations undertake to support mental health service users.

In a changing health care environment it is important that mental health practitioners, including mental health nurses, work with a variety of stakeholders including public, private and voluntary sector organisations.

The importance of the development of service user-informed provision continues to be placed at the heart of healthcare policy

(Department of Health, 2010). The drive for NHS service development to embrace the wider aspects of service users lives (i.e. social aspects) is evidenced by current funding streams (the National Institute for Health Research) and the recent location of the coordination of public health services within local authorities. Therefore, this consultation and others modelled on this are important to explore aspects beyond healthcare that are impacting on service users and the patient experience.

Despite these positive overtones, there are potential challenges in this type of collaborative venture. Although it is important when working with third sector organisations to consider all ethical aspects of the partnership, gaining ethical approval from organisations such as the NHS or a university ethics committee can be complex and time-consuming.

There is perhaps a wider debate to be had about the nature of 'vulnerability' when working with mental health service users. However, given the consultation was drawing upon research methods, it was important as researchers that we addressed all ethical issues irrespective of the challenges this may impose on the collaboration in terms of time and resources.

Indeed for any project, time and resources can impact on the outcome, and given there were no financial resources attached to this project it does highlight how difficult it can be for collaborations like this one to take place.

## Conclusions

We have reported on a recent collaboration between a third sector organisation and researchers in the North East of England to consider the impact of recent welfare reforms.

The nature of the above discussion was to highlight some of the opportunities, benefits and challenges such ventures produce. Despite the potential for practical difficulties such as gaining ethical approval and the availability of financial resources, we would advocate that mental health practitioners, including nurses, develop sustainable working relationships with third sector organisations in a variety of ways including partnership working, research and raising the profile of mental health issues.

The organisation of the NHS is changing and service users are expected to have more say and autonomy in who provides their treatment and support based on the principle of 'any qualified provider'.

It is entirely possible many third sector organisations will enter the healthcare market as 'qualified providers' and offer the type of support and provision many service users rightly demand.

Working in collaboration and partnership with third sector organisations is perhaps something mental health nurses will increasingly do in the future to further enhance the recovery of mental health service users. As researchers we found this model of co-production extremely valuable. **MHN**

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