

Evaluation of the National Survivor User Network (NSUN)

Executive Summary

for



March 2011



INTRODUCTION

The National Survivor User Network (NSUN) was created to give survivors and users of mental health services a stronger voice in shaping mental health policy and services. It brings together individuals and groups across England to learn from each other, share good practice and together influence policy makers and service providers. The service user movement in England is characterised by individuals and small local and/or issue based groups rather than a cohesive whole. Whilst they all stand for improved rights for service users and survivors, they all have their own perspectives and aspirations. This makes for a vibrant movement, but also one that lacks critical mass and a strong voice. With a landscape of small groups, running on shoestring budgets, the movement is also fragile and at risk of fragmentation and division.

In September 2006, Comic Relief agreed to provide funding of £495,450, over a five year period to support the creation and development of the National Survivor User Network (NSUN). Tudor Trust provided partnership funding of a further £250,000. NSUN's core activities are:

- ★ facilitating connections between existing service user groups and developing links with groups of underrepresented individuals
- ★ brokering and facilitating access between service users and government policy makers and statutory service providers; eg for participation on committees, responses to consultations
- ★ building capacity amongst service user groups
- ★ developing the leadership skills of service users for the movement and to enhance participation

In September 2010, Comic Relief commissioned Brightpurpose Consulting to evaluate NSUN, identifying its achievements to date, the successes and challenges so far, the extent to which there was still a need for NSUN and if so what should it look like.

PROGRESS TO DATE

NSUN had a difficult start, experiencing challenges in gaining buy-in from some parts of the service user movement. However, the board and manager addressed the buy-in issues quickly and effectively, and secured support for NSUN from early sceptics.

These difficulties were followed by a period of prolonged sickness absence and ultimately the departure of the first manager. Consequently much of the infrastructure that would be needed as a foundation for future development of the network was not put in place. A new manager was recruited in 2009. Since this time, NSUN has been making rapid progress in putting the necessary infrastructure in place and in delivering against its objectives.

These early challenges led to an underspend, as not all planned activity could be undertaken. Comic Relief and Tudor Trust agreed that NSUN could carry forward the underspend beyond the initial five year period, effectively extending the funded period by a year.

WHAT DIFFERENCE HAS NSUN MADE?

NSUN has had a number of notable successes, and has added value to members, commissioners of mental health services and policy makers. It is seen as the only national network organisation that:

- ★ is service user led
- ★ does not campaign for a particular view (except the importance of service user involvement)
- ★ is wholly inclusive, irrespective of individuals' or groups' demographic and type of mental health condition

Strengthening the voice of service users and survivors

- ★ members believe that NSUN has ensured better representation of the needs of service users and survivors

- ★ commissioners and policy makers believe that the voice of the service user is “undoubtedly stronger” as a result of NSUN
- ★ NSUN has created a framework for service user involvement, making it easier for commissioners and policy makers to involve service users and, crucially, creating a structure and continuity to it rather than it being *ad hoc*
- ★ NSUN has connected commissioners and policy makers with 260 service users who would not otherwise have had the opportunity to be involved
- ★ the National Mental Health Development Unit (NMH DU) cites NSUN as an example of “exceptional practice” in supporting service user involvement

Empowering and building capacity

- ★ NSUN shares information about policy developments and good practice, so that groups and individuals who might not have seen this information can act upon it
- ★ Members feel that NSUN helps them be well-informed about policy developments; they also feel that NSUN’s work ensures the government is aware of how policy developments will affect them
- ★ NSUN’s resources have helped local groups become more professional, well-informed and resilient
- ★ information received from NSUN has inspired service users to become active and get involved in the movement, where otherwise they would not have
- ★ NSUN has built groups’ and individuals’ knowledge of good practice, and given them confidence in sharing their work and leading others

Creating a coherent service user movement

- ★ members feel that being part of NSUN means that they are part of something bigger – from the very local right up to the national level, NSUN is creating a sense of being part of something coherent with real influence
- ★ NSUN allows different groups and individuals to come together whilst preserving their unique perspectives – they don’t need to conform to a ‘party line’ to be part of NSUN
- ★ NSUN has brokered connections between some user groups, so that they can share experiences, collaborate and become “stronger together”; further work in this area is a priority
- ★ NSUN has brought together service user involvement workers – a traditionally isolated role – to provide peer support and share experiences
- ★ NSUN’s support has helped reduced local fragmentation of service user groups, especially in the north east of England, leading to increased service user involvement in consultations and meetings about service delivery

IS NSUN STILL NEEDED?

There are uncertain times ahead, with radical changes to how health services are commissioned and provided in England, and an extremely challenging funding landscape. GP consortia will be in control of commissioning budgets, presenting both opportunities and threats for the service user movement. Service users may be well placed to deliver new, user-led commissioned services, if GPs are persuaded of the value of these; however the routes to influencing the commissioning process will become less transparent and consistent. The new mental health strategy – No Health Without Mental Health – places service user involvement at its heart, although it devolves the practicalities to a local level, with no consistent approach to how services are provided in a sensitive and user-centred way.

The service user movement continues to be fragmented and to lack a strong united voice, despite promising progress made by NSUN to date. As public funding is dramatically reduced across England, many of the small local service user and survivor groups may struggle to survive in the shorter term. There is a critical need for support from a knowledge, capacity and capability broker, that can help service user groups to improve their resilience during this uncertain period, and ready themselves for opportunities that are likely to emerge in the medium term.

In summary, the need that NSUN was created to address has not gone away; and in fact the environment has become more challenging since then. NSUN has made progress, but more needs to be done. Our assessment is that NSUN is currently the most appropriate model for continuing this work; there are no

other organisations that could take on the role with the required independence and reputation as being genuinely user-led.

WHAT SHOULD NSUN LOOK LIKE IN FUTURE?

NSUN needs to focus on supporting the service user movement through this period of uncertainty. To do this, NSUN should concentrate its efforts on its three core areas of activity:

- ★ extending reach – building the member base, reaching those not yet engaged (which might include some harder to reach and isolated individuals/groups), ensuring representative spread
- ★ empowering and influencing – continuing to build a platform for the service user voice and helping users and local groups connect in to policy makers
- ★ building capacity in the movement – capacity building at local and regional level, developing more resources to support and strengthen local groups, actively encouraging groups and individuals to link up and collaborate

Regional hubs are a powerful model for achieving these three core objectives. NSUN was always envisaged as a network of networks, and the creation of regional hubs in the other regions must be a priority action.

Any additional projects taken on by NSUN (which might be helpful in generating income and strengthening sustainability) must be clearly aligned with these three core areas of business.

It's important to recognise that, whilst highly skilled and committed, NSUN's core team is small. It is now timely for NSUN to encourage its more active and confident members to become more involved in driving NSUN forward, particularly by participating in the following activities:

- ★ promoting NSUN to potential new members
- ★ engaging new members
- ★ capacity building and knowledge sharing
- ★ networking
- ★ creating and encouraging linkages/collaboration

NSUN should also harness technology as a means of maximising effectiveness despite having such a small staff base. It's recently redeveloped website is well-liked by members and could be used to deliver:

- ★ a members' forum
- ★ use of social media to encourage networking, knowledge-exchange and gathering users' views on key topics
- ★ video and online tutorials and video based resources to support learning and capacity building for local groups and individuals
- ★ an expanded range of self-service content and resources for local groups to tailor to their needs (eg policies)

FUNDING FOR THE FUTURE

Funding will be a challenge for NSUN after the current Comic Relief and Tudor Trust grant runs out. It has been successful in securing some income-generating projects so far, and is well placed to do more of this in future – especially if it can increase its membership base and thereby demonstrate its representativeness across England. We recommend that NSUN develops a core cost recovery model that will enable it to recover core staffing and overhead costs as part of project-based funding. This would reduce its need to seek out sources of core funding. However, it is unlikely that project-based funding will secure the future financial sustainability of NSUN before its funding runs out in 2012. It will therefore need to look for funding for some aspects of its core activities, at least until 2015. By then, the landscape of mental health services will be more certain and NSUN will have had the opportunity to develop alternative models of funding – if it is still needed by then.