Evaluation of the National Survivor User Network (NSUN)

Final Report

for

COMIC RELIEF

March 2011

brightpurpose
CONSULTING

1 INTRODUCTION

The service user/survivor movement – ie the groups and individuals with lived experience of mental health services who speak out for their rights and those of others – has grown and developed in the UK in recent decades, as a result of:

★ changes in community care policy
★ an increasing focus on service user involvement in the design and delivery of services
★ the work of individuals to promote the importance of service user/survivor involvement

A number of large mental health charities also operate, some representing all aspects of mental health and others with a focus on certain conditions. The user movement tends not to see the big charities as part of the movement, questioning the extent of genuine user involvement and leadership. They also note that charities' role as providers of commissioned services presents a conflict of interests that prevents them being genuinely representative of users and survivors.

Whilst the term 'movement' indicates that all members are moving in a similar direction, the movement is characterised by individuals and small local and/or issue based groups rather than a cohesive whole. This is inevitable, as the movement encompasses people and groups representing experiences of different conditions and different care/treatment regimes. 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 for 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.

1.1 POLICY CONTEXT

In recent years, Government policy has increasingly recognised that service users and survivors have expertise in their own care requirements, and that this should be harnessed in designing sensitive and effective services for people with mental health problems. The NHS and Community Care Act 1990 led to extensive changes in the way mental health services were provided, with a strong focus on community-based care and small scale in-patient care, rather than large-scale institutions. It also mandated the involvement of service users and carers in local planning. The rhetoric of greater user involvement across health and care services has been a constant in health and social care policy throughout the 1990s and 2000s. However, even the very recent *New Horizons: a Shared Vision for Mental Health* (2009) identified the need for greater service user involvement in planning, delivering and managing mental health services. This indicates that more work is still needed to involve service users and survivors meaningfully, to bring their expertise to bear in shaping services.

1.1.1 Depth of service user involvement

Whilst health and social care providers have long been encouraged to embed user involvement in their organisations and care provision, not all organisations see service user involvement in the same way. Their perspectives can be described as sitting on a continuum from ensuring 'customer satisfaction' at the most superficial level, through deeper user involvement in the design and commissioning of services, to user-led provision of services at the other end of the spectrum. This is illustrated in the diagram overleaf.

The continuum of service user involvement in mental health
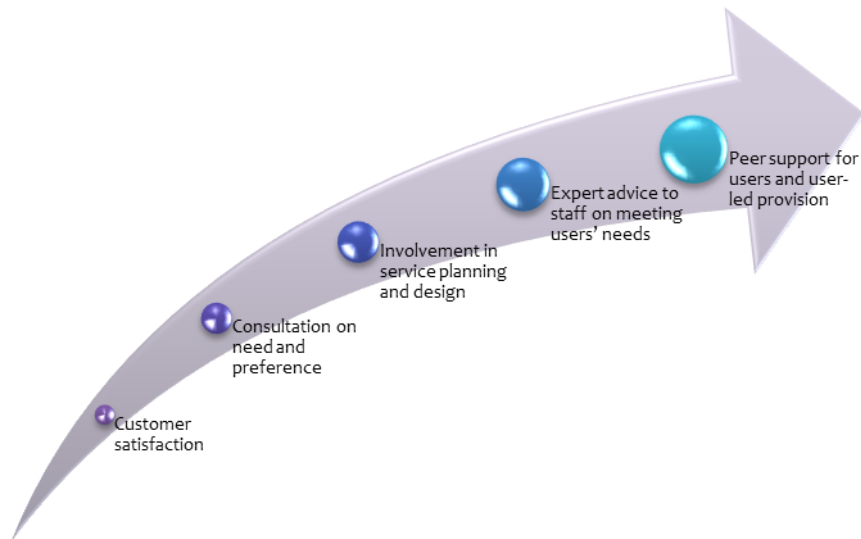
The movement is looking for meaningful and deep involvement in the commissioning and provision of services, to ensure they are appropriate, relevant and holistic. Many survivors and users are looking for opportunities and support to move away from statutory services, and continue their recovery journey with the support of peers rather than clinicians where possible. This requires a partnership approach between the commissioners of services and service users, to ensure that what is provided meets the full spectrum of needs.

1.1.2 The changing policy landscape

The new coalition government (elected May 2010) issued a white paper on NHS Reform in June 2010 – *Equity and Excellence: Liberating the NHS*. In line with the new government's localism agenda, it proposes to devolve commissioning of services to consortia of GPs, with the purpose of ensuring that commissioning genuinely reflects local need. However, this local approach poses risks of losing some of the strategic approaches to commissioning that had previously taken place at regional and local level. Commentators also question whether GPs have the capability and capacity to commission expertly across all services including mental health, which is an area that they have not been involved in commissioning in the past. Service user involvement under this new regime also risks becoming more fragmented and variable; however there is an opportunity, if grasped, for commissioners to draw on service user and survivor expertise to ensure the right mix of mental health services in a locality (including user-led provision).

★ The development of a new government mental health strategy was announced in Autumn 2010, at the time of completing the research, it had not yet been published. This lack of strategic direction from government and limited consultation on the emerging strategy, coupled with a radical reform agenda in the NHS as a whole, left some service users and groups anxious about the future direction of mental health services; and about whether their voices would be heard. The new strategy – *No Health without Mental Health* – was launched on 2 February 2011. It provides a strong policy steer that service user involvement is valued and should be at the heart of providing care for people with mental health problems. However, in line with the coalition government's localism agenda, there is little definition of how this should look in practice and local communities and providers are encouraged to devise approaches that meet local needs. Likewise there is no indication of resourcing for service user involvement in the strategy.

More generally, the new government's rapid action to reduce the budget deficit has led to deep cuts in budgets across all parts of the public sector. Even those services nominally protected, such as health, have

challenging financial times ahead. This is having a 'double whammy' effect on small community groups and the bigger national groups:

★ less money from the public sector – some are seeing their traditional sources of funding dry up, so face closure if other sources cannot be found
★ less money from other sources – charitable foundations face increased competition for their limited funds, as more projects lose public sector funding – therefore they are able to fund fewer of the bids they are receiving and must make even tougher decisions about priorities

Both of these add up to less funding for user groups and higher risk of contraction or closure.

1.2 STRENGTHENING THE VOICE OF THE SERVICE USER MOVEMENT

The Sainsbury Centre for Mental Health[1] (SCMH) carried out a survey of service users in 2001-02, which led to the production of the report *On Our Own Terms* in 2003. This set out the findings of SCMH's research into the service user/survivor movement, and made a number of recommendations for strengthening the movement. The overarching recommendation was to develop a national collaborative strategy with the aims of:

★ building the capacity of the movement to support and represent service users/survivors
★ strengthening and developing user involvement nationally and locally so that it can have a real impact on service provision
★ developing a new integrated prevention, self-management, recovery and inclusion focus for all mental health services and related social and employment services

In support of these aims, one of the specific recommendations was that the movement should be financially resourced and practically supported to build stronger local, regional and national networks.

1.2.1 Taking a network forward

SCMH established a steering group to develop a model for national and regional networks across England, support for which was latterly taken over by the Mental Health Foundation and the national charity Together. They held a joint conference in March 2006 (with a funding contribution from Comic Relief) to consult on taking proposals for a network forward. Following the conference, a group of participants formed a Network Planning Group to apply for funding to create and run a network.

A successful bid to Comic Relief and the Tudor Trust, secured funding of £¾ million over a 5 year period to develop the National Survivor User Network (NSUN) across England.

1.2.2 Enter NSUN

NSUN was created with the vision of bringing about a stronger, more united and confident mental health service user movement. Rather than duplicating existing work by service users and groups, NSUN aimed to be a 'network of networks'; with NSUN as the hub of, and adding capacity to, a network of mutually supportive and inter-related service user organisations.

The core activities of NSUN are fourfold:

★ 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

---

[1] Now known as the Centre for Mental Health

NSUN's role is to unify and support the service user movement across England, rather than speaking on behalf of it as if it were a single entity. It was not created to campaign about specific issues on behalf of its membership, but rather exists to build the capacity of members to campaign and influence more effectively themselves. With such a diverse constituency, it would not be possible to campaign on behalf of all members without excluding or diluting some members' priorities. However, a core part of NSUN's ethos is to campaign for greater service user involvement in mental health policy and services.

1.2.3 The story of NSUN

NSUN was launched in 2007. Hosting for NSUN was provided by Together – the national mental charity that had played a key role in the early consultation and development of NSUN. NSUN had its own management board and identity, but the hosting arrangement gave access to premises, back office infrastructure and the backing of a major player in mental health; it also enabled NSUN to focus on its core objectives rather than spending its early months setting up as an independent organisation.

However, the original vision for a national network had always been one where it was fully independent, and in 2010 NSUN achieved independent charitable status. As part of the move to independence, NSUN co-located with Catch-A-Fiya, a survivor-led forum for survivors from BME communities and part of the Afiya Trust.

During NSUN's life there have been management changes. The first manager was in post for several months, but left after a period of ill health. There followed a period without a full time manager whilst a replacement was recruited. The current manager joined NSUN in March 2009.

These early management challenges meant that NSUN was not operating at its planned activity levels initially. This led an underspend, as NSUN was not able to commission all the work that it had originally planned. Comic Relief and Tudor Trust approved a change to the funding agreement, allowing NSUN to use the underspend beyond the original five year funding timespan. This effectively extended the funding period to six years.

1.4 EVALUATING NSUN

In August 2010, Comic Relief commissioned Brightpurpose Consulting to carry out an evaluation of NSUN. The project was four years into its funding and therefore the time was right to take stock on progress and consider the continued demand and role for NSUN. The core questions to be explored in the evaluation were:

★ what has NSUN achieved and delivered to date?
  o what difference is this making to:
  o survivors and service users?
  o member groups and organisations?
  o policy makers and service deliverers?
  o service development?
★ what has worked well and why?
★ what hasn't worked so well and why?
★ what have been the challenges and how have these been overcome?
★ what has got in the way and how can these barriers be removed?
★ what can we learn from our experiences to date?
★ what have been the critical success factors in creating and managing NSUN?
  o how can we leverage these going forward?
★ what is different and better because we have had NSUN?
★ is there still a need for NSUN?
  o if so what should it do and how should it be structured?

The following report sets out our findings.

2 METHOD

The diagram below provides an overview of the method used to deliver this evaluation:
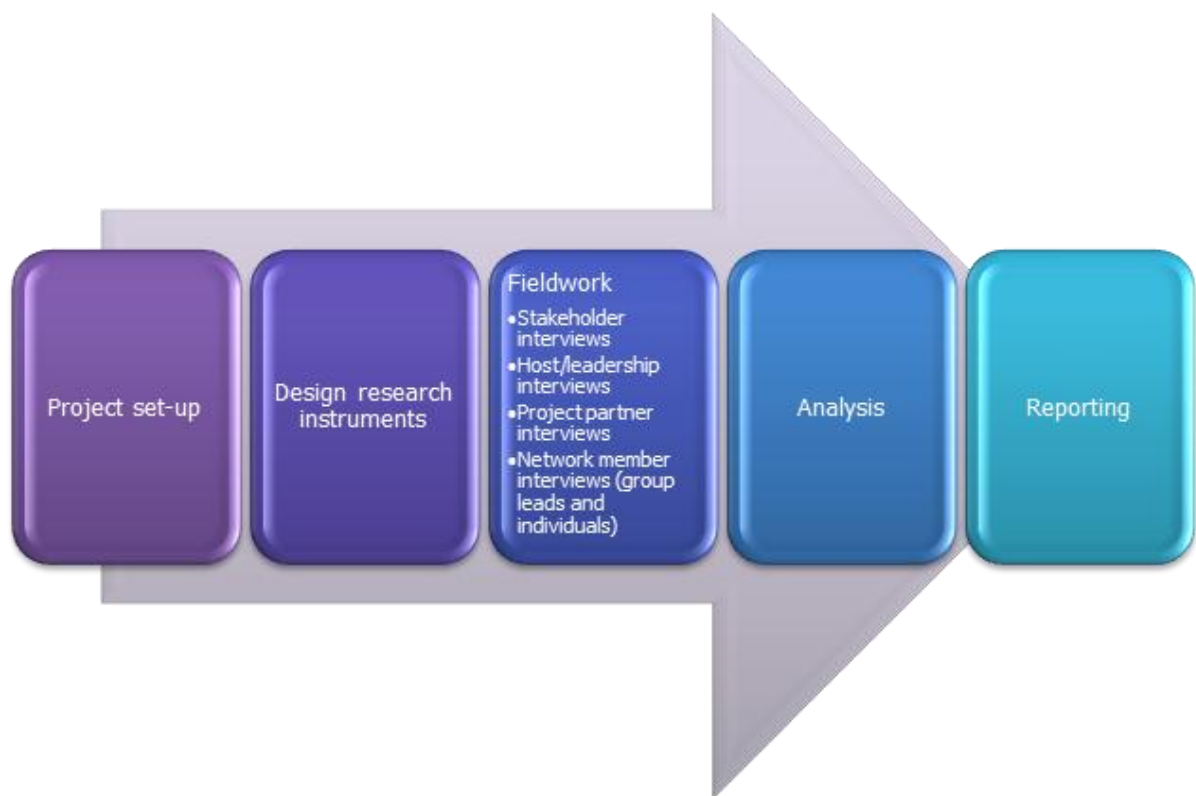
2.1 DESIGN OF RESEARCH INSTRUMENTS

Following the inception meeting we undertook a period of desk review to analyse the various project background documentation provided. We then developed a research framework which set out:

★ the purpose of the evaluation
★ who we would be engaging
★ how they would be engaged
★ detailed topic guides and surveys (what we would be asking)
★ timeframes for each part of the research

This research framework was approved by Comic Relief prior to fieldwork commencing

2.2 FIELDWORK

During the fieldwork phase we used a combination of face to face and telephone interviews to consult with:

★ identified stakeholders
★ project partners
★ regional hub leads
★ National Mental Health Development Unit (NMHDU)
★ NSUN management and leadership
★ funder organisations
★ support providers
★ members – groups and individuals

3 OVERVIEW OF NSUN DELIVERY

3.1 STAFFING

NSUN is staffed by:

- ★ 1 full-time manager
- ★ 1 full-time administrator
- ★ 2 part-time project co-ordinators for the National Involvement Project (see below)
- ★ 3 part-time volunteers

Additional IT and Accounting support are provided on a very part time basis.

3.2 FUNDING

Funding of £749,450 was provided for the period from September 2006 to August 2011 by Comic Relief (£499,450) and Tudor Trust (£250,000). This funding was to provide a combination of core staffing and overhead costs and a budget to commission projects. As discussed in section 1.2.3, early challenges in the project meant that not all planned activity took place, leading to an underspend. The funders agreed that NSUN could carry this funding forward beyond the original funding period, effectively extending the funding period by a further year.

The breakdown of NSUN's funding by year is shown below. The table also includes information on other project-based funding secured by NSUN:

Year	1	2	3	4	5
Comic Relief funding	£123,100	£136,350	£120,000	£70,000	£50,000
Tudor Trust funding	£50,000	£50,000	£50,000	£50,000	£50,000
Project based funding					
NMHDU				£83,000	£42,333
Department of Health				£15,000	£15,000
Awards for All				£10,000	
Mental Health Helplines Partnership			£3,600		
Mental Health Foundation				£5,000	£6,000
Health Care Events			£800	£600	
TOTAL	£173,100	£186,350	£174,400	£233,600	£163,333

3.3 ACTIVITIES

NSUN has been active in a number of areas, both delivering and commissioning project work, whilst undertaking the activities required to establish and develop NSUN. An overview of their key activities is provided below.

Profile and awareness raising – Extremely important in the early stages of NSUN was becoming 'known and recognised' and helping people and organisations to understand what NSUN were here to do. The work they undertake to continually raise the profile and awareness of NSUN is also crucial as it develops and grows. NSUN continues to attend conferences, seminars, events and meetings to spread the word and ensure that they remain visible and attract new members. This work is also critical for NSUN to develop alliances and partnerships with other organisations in the field.

Information dissemination and communication – NSUN communicates with its members and other interested parties through the production of:

- ★ a weekly e-bulletin
- ★ a monthly e-newsletter
- ★ bi annual publication – NSUN

This enables a stream of regular communication with the member base, keeping them up to date with developments, opportunities and the activities of NSUN. On top of this NSUN responds to member enquiries received by telephone or e-mail, actively signposts members and encourages individuals to join local groups where appropriate.

Project work – NSUN is involved in two key projects that have been commissioned. The first is the Department of Health Strategic Partner Programme where NSUN is one of 8 partner organisations who through collaborative working will work with the department to advise and inform a number of areas regarding mental health. The second is The National Involvement Project through the National Mental Health Development Unit (NMHDU). Again, this is a consortium approach, for which NSUN is the lead organisation, and the overall aim of the project is to broaden the remit of service user and carer involvement in national mental health policy. A key output from this work has been the development of a framework for involving service users and carers in policy development

Commissioning work – NSUN has commissioned two key pieces of work. The first, Dancing To Our Own Tune was delivered by Catch-a-Fiya and was a specific piece of research to investigate and assess black and minority ethnic (BME) mental health service user involvement. This report was launched in 2009 and identified actions drawn from this research are being taken forward by both NSUN and Catch-a-Fiya. The second piece of commissioned work was carried out by WISH, to map user involvement in forensic units across England. Following some editing delays, the report from this work has now been submitted to NSUN for final approval. Publication is expected imminently.

Regional hubs – NSUN has supported one existing regional hub in the north east and supported the creation of a hub in the south east; it continues to support the development of both. Mapping was carried out in each of the hub areas to identify the service user groups and other key contacts, with a view of bringing them all together as part of the regional network. There are bi-monthly meetings between NSUN and the regional hub leads as well as meetings with local commissioners. On top of this each regional hub creates and maintains an issues log which is informed by service user experience. NSUN has also been in talks this year, in the north west, the West Midlands and London with a view to establishing further regional hubs in these areas. Once successful this will result in more than half of the English regions having their own regional hub.

User Involvement Workers Peer support group – Established in 2009, the User Involvement Peer Support Group was established to enable those who are working in user involvement roles to access peer support. The group currently has 20 members from across the country who meet on a regular basis, with meetings being facilitated by an independent consultant. The meetings gives attendees the opportunity to share experiences, challenges, good practice and to discuss current issues in a structured way.

Peer2Peer group – Although led by Together, NSUN is an active supporter of this group and is instrumental in the promotion of the group and its objectives. Essentially the group is made up of service user led organisations that are tasked with leading on peer support in their areas.

Website – Having a web site with fit for purpose functionality is crucial for a network oriented organisation. The newly launched website took time to develop but the feedback from the NSUN manager and members suggest that it has been a worthwhile investment. The website is a critical tool for connecting members and for the dissemination of information

NSUN organisational development – As well as the 'outward facing' activity undertaken by NSUN it is also worth noting the activity that they are undertaking to develop the organisation. NSUN has been supported through the Pilotlight project, which 'matches' business leaders with 3rd sector organisations to provide strategic support. The support through the Pilotlight project, and work undertaken by NSUN as a result of this support, has helped with the strategic direction of NSUN, understanding their strategic

priorities, and putting focus around their aims and mission. They continue to receive this support and over the coming months will be investigating options for the future including sustainability.

Facilitating/brokering access to service users – NSUN has noticed an increase in the number of organisations that are now approaching them to facilitate or broker access to service users to inform certain initiatives, research or pieces of work.

Leadership training – Although not widespread across the country, NSUN has delivered training in the regional hub areas to develop service users' capabilities to be effective consultees.

3.4 REACH

At present it is difficult to be precise regarding the exact number of NSUN members. Due to different databases being held for members involved in project work (eg through NMHDU) and those that are members through the regional hubs, as well as the master member database, a definite number cannot be provided. However, details are provided below in relation to the member numbers held on each of these databases:

★   NSUN main member database – 641 (121 groups, 505 individuals and 15 'allies')
★   North east member database – 250 (no breakdown of groups and individuals provided)
★   South east member database – 120 (13 groups and 106 individuals and 1 'ally')
★   NMHDU database – 270 (users and carers)

The total membership base across these databases totals 1,281. Taking in to account that there will be a degree of duplication across the databases it is reasonable to expect that the number of unique users will be somewhere between 800-1000 members.

NSUN is currently in the process of merging these different databases in to a single database and carrying out a de-duplication process to ensure no member is 'counted' twice. Once this has been completed an accurate picture of member numbers can be provided, and commentary on the perceived success of NSUN's reach can be made.

4 FINDINGS – STAKEHOLDER CONSULTATION

This section draws on information gathered through a programme of face to face and telephone interviews with 28 stakeholders from a range of organisations, including:

★ funder organisations
★ NSUN
★ regional hubs
★ commissioners of mental health services
★ national charities and service providers
★ NMHDU
★ partner organisations

4.1 CREATION AND EARLY DAYS

Following the creation of NSUN, the initial priority was to raise its profile amongst other organisations operating in the mental health sphere, as well as amongst existing groups, networks, forums and individual service users and survivors. The feedback received from stakeholders suggests that some parts of the service user movement perceived this early activity as insufficiently consultative; they felt that they were being presented with a *fait accompli* – 'this is who we are and this is what and how we will do it' – rather than involving them in shaping NSUN. This created some early tensions and suspicion from some parts of the movement. Whilst there had been the conference to develop the proposals for NSUN, this was only attended by 170 people, and some perceived the process as exclusive. Stakeholders reported that the NSUN leadership quickly recognised the suspicion and tension that was building, and took effective action to have a more open dialogue and consultation with a wide range of partners. Stakeholders praised NSUN's leadership for the action they took to build bridges and bring people on board after a shaky start.

The hosting arrangements with Together were reported to have had both pros and cons for NSUN. Many stakeholders reported that this hosting arrangement was in fact a critical success factor for NSUN. It provided them with structure, support and ready established processes, which enabled NSUN to 'hit the ground running' and develop a solid foundation to build from in a supported environment. However the flip side was that some of the processes that NSUN had to follow were perhaps a little cumbersome for such a small organisation. More critical than this, though, was that many organisations in the mental health arena did not recognise NSUN as either an independent organisation, and questioned whether they were user-led during this hosting period. They perceived NSUN as 'Together's baby'. Although this inevitably had an impact on attracting members and being recognised and accepted by organisations already established in the field, the majority of stakeholders still believe that on balance a hosted approach was the correct one. In addition, it has provided valuable learning for Together, the hosts of NSUN, in terms of how they would provide a hosting service in the future.

Getting the right staff to drive the initial development stages of any organisation is crucial. Stakeholders reported that the first manager of NSUN was poorly organised, and did not create and develop the infrastructure needed to deliver NSUN. From the funders' perspective this resulted in a lack of clarity in relation to reporting and understanding what was actually being delivered. For example, actual member numbers were not clear during this period as the database was not developed. This was compounded by the first manager having a period of long term sickness. Whilst staff sickness is a fact of life in any organisation, it did lead to further delays and uncertainty at a critical time in NSUN's development. Stakeholders noted that periods of ill health are a risk for any small organisation, and long term absence can have a profound effect. They also acknowledged that, whilst the manager's absence was a result of physical rather than mental ill health, user-led organisations have an added layer of vulnerability in terms of potential staff absence; to ensure a resilient service user-led organisation, stakeholders suggested that staff contingency plans were essential.

4.2 INDEPENDENCE

Feedback from stakeholders suggests that the independence of NSUN happened at the right time for the organisation, and that it was a smooth process. It is widely recognised by stakeholders that it was essential for NSUN to come out from under Together's wing and present itself as an independent organisation in its own right.

*"Independence has been an important milestone for NSUN..........
it is vital that they have their own identity"*

*"They have clearly created a good structure and established themselves as fully independent.
That takes a while, to get to be autonomous"*

NSUN's positioning with Catch-A-Fiya is perceived as a good co-location option, with excellent complementarity. Tactically it was also helpful to both parties. Service users from BME communities tend to be one of the more under-represented groups, in terms of user and survivor voice. The fact that Catch-A-Fiya was in a position to offer a co-location option for NSUN sends a very positive message about the capacity of this survivor-led forum, and the joint work done by the two organisations demonstrates NSUN's commitment to supporting a stronger voice for BME service users and survivors. The support the two organisations have offered to each other has been mutually beneficial.

*"It's more than sharing office space, we share experiences and
look for areas where we can collaborate"*

NSUN's step to independence was also critical in removing the last shreds of cynicism amongst the observers who refused to recognise NSUN as an organisation in its own right.

4.3 CURRENT MANAGEMENT AND LEADERSHIP

The members of the NSUN board and the current manager have both been reported as critical success factors in the development and success of NSUN. Collectively they are seen by stakeholders as being committed and driven, whilst providing the level of organisation that was required to establish the working structure of NSUN. The board members each bring their own area of expertise, skills and/or knowledge that is vital in directing and supporting the manager to achieve NSUN's ambitions.

As with any young, developing organisation there have been changes to board membership along the way. This is reflective of the evolution of NSUN, and recognises the need to bring in different people with different skills and expertise at different stages of the organisation's development. This is a good thing, and something that should continue to happen on an on-going basis. It is vital that they continue to step back, take stock and understand the skills and expertise they will need from their board as NSUN continues to develop and grow.

*"They need to stay mindful that the individuals they have on their board now are not
necessarily the same people they will need as NSUN develops"*

The openness, willingness and level of self-awareness of the NSUN manager and leadership team in recognising the need for organisational development support was reported as impressive. In our experience and that of Pilotlight, the organisation that is facilitating this support, it is not common for such a young organisation to recognise the need for and be so open to this. The support work has required a large time commitment from the manager and board, but has assisted NSUN in gaining a focus and clarity around what is needed from the board members and in developing a strategy for moving forward. This work is on-going and, as it progresses, will begin to investigate the sustainability options for NSUN. Feedback from Pilotlight has been extremely positive. In their experience the NSUN team have been dedicated and committed to the work undertaken so far and have 'stepped up to the plate'. They have

completed any required work to a very high standard. This support has also been complemented by regular coaching and mentoring sessions for the manager through an independent consultant who has also delivered board development days for NSUN.

The NSUN manager was seen by many as the driving force behind NSUN, with many stakeholders speaking positively of her energy, determination and willingness to work together with others.

"The passion and commitment of the NSUN manager, and her willingness to work with partners and engage organisations and individuals has been a big enabler"

Although the manager also has some support staff, the team is still seen to be operating 'on a shoestring' with minimal people resource. This makes NSUN fragile and vulnerable to staff absence and the potential challenges that this would present (as seen during the absence of the previous manager). In addition to this, NSUN is operating at capacity – they are now in the position where any additional work or responsibility will currently require a trade-off – do less of something so that they can do more of something else. This will require careful planning and execution as NSUN moves forward.

4.4 AMBITIONS FOR NSUN

Stakeholders shared fairly consistent ambitions for NSUN. Their hopes are that NSUN would:

★ reduce/remove the current level of fragmentation in the service user movement
★ empower service users and survivors to have a voice and make that voice heard
★ build and develop the capacity of local service user and survivor groups (and individuals), enabling effective influencing at a local level through a local voice
★ create a national platform for the service user and survivor voice
★ create a chain from individual to local group to regional group to national network – helping to reduce the aforementioned fragmentation
★ influence policy – nationally and locally

An enabler for all this activity is the formation of influential relationships with Government and other organisations, which NSUN is reported to have been successful in doing. However, the majority of stakeholders believe that the reach of NSUN, in terms of its member base, is more important. This presents a chicken and egg scenario: individuals and groups will become members if NSUN is recognised as being influential, yet it can only continue to build its influence if it is perceived as representing a large membership.

"To get a seat at the table with the Department of Health says a lot.............NSUN have a real opportunity to influence service user involvement"

Another important differentiating factor of NSUN, in relation to the ambitions for NSUN, is that it is not trying to be or claiming to be the voice of service users and survivors, rather it is about giving service users and survivors their own voice and helping them to be heard. It is a platform rather than a mouthpiece.

Although no stakeholders expected that NSUN would have met or achieved all the ambitions detailed above at such an early stage, there were a number of positive reports that they were making good progress towards them. Although NSUN's reach was described by some as good for the stage they are at, it was recognised that they have not reached the critical mass of membership that would be required to meet these ambitions in full. This is a work in progress.

"It's making progress now. They got off to a rocky start and things went dead for a bit, but it's picking up now"

4.5 ADDED VALUE OF NSUN

Stakeholders commonly reported that they did not see any areas where NSUN was duplicating or replicating anything that is already available, in terms of support for service users and survivors. What they had observed led them to believe that it complements and adds value to existing support.

NSUN is seen as the only national network organisation that:

★ is service user led
★ does not campaign a particular view
★ is wholly inclusive regarding individuals' or groups' demographic and type of mental health condition

"NSUN is a unique organisation – it is filling an obvious gap, It does something different and doesn't duplicate what is already out there"

In addition to this, there is a sense amongst stakeholders that NSUN allows members, whether they are individuals or groups, to maintain their own identity whilst joining and benefitting from being part of 'something bigger' – they do not have to conform to a particular view or agenda to be a member of NSUN. This also relates to the perceived impartiality of NSUN. This in part is due to NSUN not having a service provider arm to the organisation (in contrast with many of the large mental health charities) and therefore having no real conflict of interest in relation to policy developments and changes that would affect service delivery. Most stakeholders believe that this should always be the case for NSUN, though with potential for NSUN to support local groups to become providers of mental health services.

"NSUN are supporting smaller networks to build their own capacity.........they provide value and support, whilst giving a sense of belonging and strength in numbers"

NSUN's work in helping to make and facilitate connections between individuals and groups at a local level is something that simply would not have happened without NSUN. Through this, NSUN is beginning to create a coherent 'chain' from individual up to national network. Stakeholders said this was particularly valuable, as users felt part of something bigger. In addition, feedback from a user involvement worker who works with statutory service providers in the North east was highly complementary of NSUN's work. They reported that NSUN had made a huge contribution to reducing the level of fragmentation amongst local and regional user groups in the north east of England. They also cited examples of how NSUN had supported these groups to 'become stronger together' and support their influencing activities, which has seen an increased involvement from service users in consultations and meetings regarding service delivery. Although this facilitation of connections seems to be happening more in the regions where NSUN has been supporting and developing regional hubs (though not exclusively), it will provide valuable learning for NSUN in terms of how they facilitate and encourage these connections on a much wider geographical basis. It is the enablement and encouragement of these connections that will build the strength of the local voice and capacity of local organisations to influence effectively.

NSUN's activity around information dissemination is also seen as a source of added value. It is recognised that it is very difficult for small groups and organisations to remain abreast of developments, changes, consultations etc relating to mental health. NSUN have been successful in becoming the conduit for this information, ensuring it reaches all of its members and partner organisations.

"There can be so much information out there and small organisations often don't have the knowledge or resource to gather it
...........having NSUN gather and share this with members can make such a difference"

Another area of added value is through the support they provide to service user involvement workers. The role of a service user involvement worker is often an isolated one, with individuals in these roles having very little support (and in some cases understanding) from within their own organisations. It is also a

crucial role in relation to service users having their voices heard at a local level. NSUN, through its 'Service User Involvement Worker Peer Support' project is giving people in these roles the opportunity to meet with others delivering the same role, from different areas of the country and from within different organisations. This enables the sharing of good practice, experiences and learning, and also provides a much needed support network for service user involvement workers. It is questionable whether the size of this project, in terms of service user involvement workers engaged in the group, will generate significant impact, but for those involved and stakeholders who have observed the sessions it is providing some benefit that would not be realised otherwise.

"It gives me the opportunity to meet people that are in the same role as I am. It's nice to know that you are not the only one facing the challenges you face and it's a great help to be able share this with others and learn from each other"

NSUN is becoming, in the eyes of several stakeholders, the 'go to' organisation when service user and survivor involvement is required for a specific piece of work or initiative. This has simplified the process for a number of stakeholder and project partner organisations as well as government departments (ie NMHDU). Specifically, NMHDU reported that although they have always communicated with service users and survivors, NSUN has brought a continuity and structure to how they do this.

4.6 WHAT HAS WORKED WELL AND WHERE HAVE THE SUCCESSES BEEN?

Stakeholders identified a number of successes and examples of things that have worked well. We present the common themes from this below:

NSUN website – NSUN's newly launched website was widely reported as a key success and a huge improvement on the previous website. The functionality and usability of the website are far better than the old version and makes the user experience far better. A critical aspect of this has been the functionality that enables members to find and connect with other members. This is reported as being a much easier, simplified and straightforward than it had been before. This is, of course, crucial to enabling NSUN to develop the coherent chain that we have discussed in previous sections. The new website also caters for visually impaired users, which is something that is often neglected.

Getting a place at the table – In addition to being well-recognised and well-regarded by others in the mental health sphere, stakeholders see it as a great achievement that NSUN is working with the Department of Health (through the strategic partner project) and the National Mental Health Development Unit (through the National Improvement Project). This reflects the profile that NSUN has achieved in a relatively short space of time, and offers the opportunity to influence at a national level.

"NSUN is bringing in the service user voice. A lot of organisations out there provide services but NSUN is about bringing the user voice in at the highest level"

Regional Hubs – The creation and development of the two regional hubs in the North East[2] and the South East is viewed as a success, and the approach is seen as an important aspect in the future evolution and progress of NSUN. Due to the limited resource that NSUN has at its disposal, it will be dependent on 'leaders' at a regional level to be active in terms of awareness raising, gaining buy in and growing the membership. This role has the potential to expand further with regional leaders becoming instrumental in supporting local groups and individuals to build capacity and confidence. It should be noted though that a few stakeholders did expect there to be more regional hubs in place by now. Talks are on-going in at least two other regions at present and it is the aim of NSUN to have a regional hub in each region of England.

---

[2] The North East hub was already in existence, but NSUN support has helped bring the north and south subregional groups together more effectively and support the strengthening of the regional hub.

Commissioned work – NSUN has commissioned what are viewed by stakeholders as two important pieces of work. The first is piece of work, *Dancing To Our Own Tunes*, which set out to assess the user involvement from BME communities, traditionally one of the most under-represented voices. Following the launch of the report NSUN is now working with Catch-A-Fiya to develop and implement identified areas for action. The second piece of work involved the commissioning of WISH to map the extent of service user involvement in forensic units across England. One stakeholder commented that this was a much needed area of work and one which most organisations wouldn't have attempted given the complex nature of the information collection involved.

National Mental Health Development Unit – National Improvement Project (NIP) – As well as stakeholders recognising the success of NSUN in winning this work from NMHDU, the department itself was highly complimentary of NSUN's work. They believe that the voice of the service user is 'undoubtedly stronger' through the work of NSUN, and provided an example of what they deemed to be exceptional practice; As part of the NIP work, NSUN developed a framework for delivering consultations and involving service users which NMHDU believes has applicability across all public sector consultation work.

Joint events - We heard numerous examples from stakeholders and partner organisations about joint events that they had run with NSUN. This was seen as efficient use of resource as well as projecting an inclusive image. In addition to this, stakeholders spoke of NSUN's openness and willingness to work in partnership with others. This is another factor in ensuring that NSUN is not duplicating or replicating the work of others.

NSUN profile and image – Stakeholders reported that NSUN has done incredibly well to achieve credibility in the mental health sphere and build productive relationships with 'key players'. In a relatively short space of time they have become 'known' – organisations in the field know who NSUN are and what they do.

Credibility with BME groups and organisations – Catch-A-Fiya reported that NSUN is one of the very few networks, outside of those with a specific BME focus, to achieve credibility with BME groups and organisations. Considering that BME groups are amongst those most under-represented in the service user movement, this is a key achievement.

4.7 WHAT HAS NOT WORKED SO WELL AND WHAT ARE THE CHALLENGES?

It was encouraging that stakeholders could not easily point to any areas that they believed had not worked so well, however some common themes did arise. These are discussed below:

Limited resource to do a big job – Stakeholders recognised the enormity of the task in developing a network and achieving a critical mass across the country. There is some concern that NSUN is not resourced sufficiently to achieve this. Although they recognise that much has been achieved to date, they also recognise that there is still much to do. Stakeholders have suggested that they need to make the most of technology and make use of their member base in order to increase NSUN's capacity and reach.

> *"they have a very small infrastructure. That was deliberate, but there are not enough man hours and resources"*

> *"good reach but they've got capacity issues"*

Type of member – A few stakeholders suggested that the current member base was likely made up mainly of individuals or groups that are already motivated and keen to engage. Their concern is that it is the layers underneath this that are most important, and are those that perhaps need the support of a network more than others. It is also recognised that it is these layers beneath that will be the hardest to identify and engage.

Slow in starting – we have already discussed the various issues and challenges that NSUN faced, and overcame, in its early days. Stakeholders commonly cited these issues as areas that had not worked so

well but also went on to say that they done extraordinarily well to overcome them and come out the other side.

More to do at a local level – Although stakeholders see the regional hubs as one of the successes of NSUN, a few had expected there to be hubs in other regions by now. Furthermore, stakeholders reported that more needs to be done at a more local level – a layer below the regional work. They would like to see more activity that engages and builds the capacity of local groups and individuals. Expansion of the regional hubs would certainly help this, by utilising regional leaders to help drill down further and raise awareness of NSUN.

4.8 THE REACH OF NSUN

When we spoke with stakeholders about their perceptions of the reach achieved by NSUN, in terms of member numbers and geographic spread, we heard a wide range of opinions. This spanned from those who believed that the reach achieved to date had been excellent through to those who feel that, whilst it has done well in a few geographic locations, much more was still needed. There were also stakeholders who did not feel that they could provide an informed opinion on this.

4.9 CONCERNS REGARDING THE EMERGING POLICY LANDSCAPE

Stakeholders raised a number of concerns regarding the emerging policy landscape. They included:

★ *GP commissioning* – It is widely recognised that GPs will need help in understanding the needs of service users and survivors, but there is a concern that they will not know how to go about this. Likewise for service users and survivors, they will be required to connect with even more commissioners and need to understand how they would do this. NSUN has an important role in this.
★ *New mental health strategy* – at the time of our research, stakeholders expressed concern that the new mental health strategy was being developed in isolation by medical professionals, with little inclusiveness or consultation. This was creating a worry that policy might be moving back towards a medical model. Since then, the new mental health strategy has been launched – *No Health Without Mental Health*. The strategy, rather than representing a step back to the medical model, appears to build on the principles of the previous government's mental health strategy.
★ *Changes to benefit system* – the new government is moving to a new single benefit system over the coming years. In the meantime, there is a review of eligibility for Incapacity Benefit claimants who have recently been moved over to Employment Support Allowance. This is currently being piloted in two areas, but the feedback indicates that many claimants with changeable conditions (including mental health conditions and physical conditions such as Multiple Sclerosis) are being assessed as able to work and therefore no longer eligible for incapacity-related benefits. This is causing a great deal of worry for people in the user movement, many of whom are already financially challenged as a result of their condition.
★ *Budget cuts* – The impending budget cuts create a number of challenges and concerns. The first is that there will be even less money than in the past for service user involvement, from the NHS and others. With fewer funding opportunities there is also the likelihood that user and survivor groups will 'go under' unless they develop their capacity or collaborate with other local groups. NSUN has a key role in facilitating this capacity-building, or in making connections between local groups. The final aspect of the budget cuts to be considered is that of staff redundancies in various government departments (and in some cases the disbanding of certain departments altogether). NSUN has invested time and effort in developing relationships and becoming 'known' by staff in government departments; the worry is that these evaporate as staff move on, reducing NSUN's level of influence with policy makers
★ *Big society* – This is an area that potentially provides opportunity for the service user movement. There is scope for service users to provide user-led services – though this can only happen if groups have the capacity and capability. Quite how the big society will 'work' is still relatively unclear, and it may simply rely on the goodwill of the volunteer sector; as there is a strong volunteer culture amongst service users and survivors this may be exploited, removing the potential opportunity mentioned above.

4.10 FUTURE SUSTAINABILITY

There was a clear message from stakeholders that NSUN is facing a number of challenges regarding future sustainability. It is the view of stakeholders that NSUN will require a combination of both Government and charitable money going forward. The feeling is that NSUN is not yet far enough advanced to develop income generation models that would enable it to be entirely self-sufficient. The delays and issues in the early stages of NSUN's development mean that it is 18-24 months behind where it potentially could be. Although NSUN has been successful in winning specific pieces of work that generate income, as has been mentioned previously, this must be balanced with the core activities of NSUN ie building the member base and developing the capability and capacity of local user groups. This activity does not generate income and therefore, in the short to medium term at least, core funding must be secured from somewhere.

The pressure on Government budgets may mean that more organisations and projects are seeking funding from charitable foundations. This heightens the pressure on charitable foundations and they will have to be even more selective about which projects and initiatives they will fund, based on the value they add and impact they will generate. In addition, it is questionable whether NSUN has enough reach in terms of its membership to justify government funding as a national, representative forum for the service user movement – again it is about achieving the critical mass.

It is worth noting that the future of NSUN, and its sustainability, is an area that they are receiving support to investigate and develop through the Pilotlight project.

4.11 IS IT NEEDED IN THE FUTURE, AND IF SO WHAT SHOULD ITS REMIT BE?

The vast majority of stakeholders reported that there was still a need for NSUN going forward. The job it was created to do is not yet done, though they believed that relatively good progress towards this has been made. In addition many stakeholders reported that, in these uncertain and changing times the need for NSUN is greater than ever.

The next few years present what could be some of the most challenging times for the service user movement – the funding challenges that will put service user and survivor groups at risk of closure, new commissioning models being introduced, concerns about a potential shift back towards a medical model. The support that NSUN can offer to groups and individuals through these times will be critical. NSUN have a role to provide opportunities to build capacity and resilience, supporting groups to come together to voice concerns and influence commissioners and to act as a conduit for user's voices into national policy makers.

If NSUN was to cease operation, stakeholders believed it would essentially undo the work and achievements of the past 4 years. They reported a risk that it would create disenfranchisement amongst members of the service user movement that have engaged with NSUN and that this could have lasting implications for any future attempt at establishing a network of this type. In having a national network for the service user and survivor movement, it is suggesting that the movement and its opinions and voice is valued – take it away and it will send the opposite message.

"NSUN has made good progress in reducing the level of fragmentation amongst the service user movement...............if NSUN was to go there is a strong chance that it would create a disillusionment amongst service users and undo the work which has already been done"

In terms of NSUN's remit going forward, the feedback suggested the following priorities:

★ expanding the membership – as has been said many times through this report, reach is critical. NSUN needs to be reaching further – achieving a geographical representation in its membership, getting underneath the layers to engage the most isolated

- ★ more regional hubs – stakeholders see the two established hubs as an achievement, and want to see more of them. Establishing regional hubs is potentially an effective means of extending reach into local groups and individuals, and getting beneath the layers as previously discussed.
- ★ more local activity – more activity is needed to be building the capacity and capability of local groups. Giving them the skills and confidence to influence at a local level, as well as facilitating the connections between local groups and individuals
- ★ influence at national level and empower members to influence at a local level – a key role of NSUN as it moves forward is to continue its activity in influencing policy at a national level, whilst also empowering local groups and individuals to influence locally
- ★ campaigning for increased and meaningful service user involvement across all parts of the mental health system
- ★ information dissemination – to continue to disseminate information and intelligence to its members and partners.
- ★ project work – NSUN should continue to deliver project work which not only generates income but more importantly, continues to build the profile and reputation of NSUN and enables it to have a greater degree of influence.
- ★ making connections – it is one thing to build the membership base, and have groups and individuals as members but the real value comes from linking these individuals and groups and helping them to see the value in working together in their local area, learn from each other and draw on one another's strengths and resources.

A couple of stakeholders did suggest that the future remit of NSUN should involve active campaigning. Whilst NSUN has a pivotal role in campaigning for increased service user involvement in mental health service, it has always been deliberate about not being an issue-led campaigning organisation; the majority of stakeholders still believe this to be the right thing. NSUN recognises the diversity of views amongst the service user and survivor movement, and for NSUN to take a public stance or view on specific mental health issues other than service user involvement would potentially isolate sections of their membership (and potentially put off new groups or individuals from joining). NSUN is there to enable or at least provide the opportunity for every individual and group to have their own voice, rather than to align itself with a particular view or agenda.

4.12 GOING FORWARD – THINGS TO CONSIDER

Stakeholder reported a number of areas that NSUN would have to consider as they move forward. These are summarised below:

Resource – As NSUN operates with a very limited 'people' resource, which is likely to be the case for their immediate future, they need to make the most of the technology available to them in order to work as efficiently as possible. There were suggestions made by stakeholders around the potential for using video tutorials as a training and/or capacity building resource. In addition, the website has the functionality that enables members to contact each other through NSUN, and a couple of stakeholders wondered whether this could be taken a step further in terms of social networking (eg a forum of the website, where members can start topics that other members can input to and discuss). This would also help to further facilitate links between members.

Utilising the member base – In order to maximise its reach and effectiveness, NSUN needs to look at how it can best utilise it member base. There is much willingness, skills and experience present in the membership and NSUN should investigate how this resource can be used to support the work of NSUN, attract new members and develop the capacity and capability of local groups and individuals.

Balancing their activities – We have mentioned previously the need for NSUN to be active in project work that raises the profile and reputation of NSUN as well as increasing their level of influence. However, this must be carefully balanced to ensure that NSUN maintains the capacity to continue delivering its core activity, in relation to building the member base and building the capacity and capability of members

Remain focussed – Going forward NSUN will need to maintain its focus on its core aims and objectives, and deliver the activities that contribute towards achieving these. Stakeholders recognise that there is

potential for lots of people to want lots of different things from NSUN – it cannot be all things to all people, and the best way forward is to ensure that NSUN delivers its core work well rather than trying to do lots of things and doing them poorly.

Collaboration – Just as NSUN should be helping its member groups and individuals to link with each other, NSUN should also be active in identifying areas for potential collaboration with other organisations and partners. This of course needs to be aligned with work/activities that contribute to the aims and objectives of the organisations involved, rather than collaboration for collaboration's sake.

The 'go to' organisation – NSUN are becoming known as the organisation to go to for service user involvement. This is an important space to be occupying, and development of this will happen naturally through effective awareness and profile raising, building their reputation and active influencing.

5 FINDINGS – NSUN MEMBERS

This section draws on information gathered through a programme of telephone interviews with 15 NSUN members, and is supplemented with data gathered through a recent survey of members which was carried out by NSUN. The survey had 98 responses.

5.1 MEMBERS' EXPECTATIONS FOR NSUN

The majority of individuals and groups involved in this evaluation see their membership of NSUN as a potential way of:

★   learning good practice
★   sharing their own knowledge of what works
★   developing their own skills in leading and training others

Many had been active in the service user and survivor field for some years and were initially keen to see local and regional networks communicating with each other in a more co-ordinated way. A minority also worked with carers of service users and wanted to ensure their voices were also considered.

A few respondents were present at the original conference to define the role of NSUN, and felt strongly at the time that a means or mechanism for facilitating more joined-up thinking was a crucial and much-needed step. Respondents wanted to be able to pick up the telephone and speak to others for support and to be given the opportunities to interact face-to-face with peers from other regions.

5.2 PERCEIVED CONTRIBUTION AND VALUE OF NSUN

The majority were positive about NSUN's contribution to both promoting the voice of service users and survivors – something that is seen as one of NSUN's key objectives – and building the capacity of individuals and groups. However, views were divided about the extent to which NSUN has improved connections between service user groups and organisations across England, even though all perceived this to be its most principal aim. Around half reported that progress had been made, though more was needed; the other half reported little or no progress against this aim.

The results of the NSUN member survey suggest that the overwhelming majority (74%) of respondents had a positive perception of NSUN, whilst 23% reported that their perceptions were neutral or other. Only 3% reported having a negative view.

5.2.1 Improving connections with other service user groups and organisations

Members were very keen to emphasise the importance of NSUN's function in providing regional and national linkages between different individuals and groups. For most, there was perceived to be a fragmentation and critical lack of communication between those working within the service user and survivor field. A few members recalled NSUN being the outcome of the initial conference in Birmingham and how this was felt to be a very real opportunity to start working together, sharing good practice but also understanding what does not work in supporting others who are service users, survivors and their carers.

> *"I was in touch with other networks before NSUN was born, a national network seemed to be a good idea, a facility for people to speak more readily to each other"*

> *"NSUN is unique. There isn't another national voice that is entirely service user-led. There has been a huge gap for a long time"*

However, only around half of the members interviewed feel that progress had been made in achieving this goal. Even in these cases, it was suggested that this is merely the beginning and that NSUN should be

focusing its future priorities on strengthening these connections. Although the website was frequently mentioned as a great information source for finding others in local areas and other regions, there was a real sense that more could be done in terms of:

★ ensuring the building of networks in specific regions
★ introducing more opportunities for face-to-face interaction with others

A few members who participated in this research would like to see a more concerted effort to develop capacity in areas that are not currently well linked at local level or where there is only a minimal presence from service users and survivors. However, in part this is also about equipping members with the skills to help facilitate this process. Those who had received training from NSUN and/or attended other events were very positive about the impact of this on improving their skills and confidence in 'doing their bit' to help develop links within and across regions.

A few felt that only a very minimal amount of work has been done by NSUN to improve networks. In these cases, this was due to a high expectation of NSUN to be creating opportunities and approaching members with these – actively making links on behalf of members. This was the exception rather than the rule. Most accepted that they also had a responsibility to help make this happen. Within the NSUN survey responses the findings show that roughly 22% had contacted another NSUN member after hearing about them through NSUN. This suggests that perhaps more does need done to encourage members to be proactive in making these links themselves.

> *"I haven't made any contacts. I thought there would be a regional group of users. I was expecting more information about that"*

Respondents to the NSUN member survey also reported that NSUN was helping them to connect with other people, either in their local area or further afield. However, as with the telephone interview findings there were also a small number of members who did not feel that enough had been done to actively connect groups and individuals.

Those that have been more proactive about finding and making links with other groups also expressed that this was due to NSUN. There was also a sense from survey respondents that NSUN has increased the perceived professionalism and profile of service user involvement

5.2.2 Providing access to resources and support
NSUN's website has been highlighted as a real benefit of becoming a member, holding an extensive range of information that is of relevance to service users and survivors. A few were specific about a recent overhaul of the site and the improvements this has brought and will continue to bring to members, including relevant and 'up to the minute' policy documents as well as a directory of members. The newsletter is also seen as a good source of information, offering interesting information and insightful news stories.

This has made a real difference for some individuals and organisations in helping them to feel knowledgeable and involved in what is going on and appears to be particularly effective in regions with a reported low level of organisation and communication between existing networks. This finding was also apparent in the findings from the survey responses.

> *"We now know about other events happening. We are not so isolated now. We know about the latest developments"*

The NSUN member survey findings suggest a similar view. Members were asked in the survey, what NSUN actually does for them. A large proportion of respondents cited the dissemination of information, intelligence and knowledge carried out by NSUN was proving very valuable to them and their members. The impact of this, as well as keeping people informed of national developments and what is going on in other parts of the country, is helping people to feel less isolated and part of something bigger. In addition

to this, members also reported how the information they received from NSUN inspired them to be active and get involved.

5.2.3 Building capacity and providing stronger service user leadership

Many members reported that NSUN has helped to build their own capacity and a few feel they have also been able to develop their own leadership skills. As most had already been involved in the field for a while as survivors themselves and in co-ordinating links at local level, they feel they have certain skills such as communication and creating new approaches – skills which they feel have been confirmed and further developed as a result of being part of NSUN and attending training and seminars. A few members mentioned the value of resources available on the site that can be downloaded and adapted to form frameworks and approaches in different regions.

> *"[NSUN has] formalised my own ideas, my own ambitions for service users"*

> *"[NSUN has] definitely helped to build capacity. We have got policy things off the website – health and safety policies. We downloaded a number of skeletons and adapted these to the group"*

This increase in capacity is also due to feeling better connected and informed. Respondents have reported that they have been able to lead developments in their organisation or in their own activities as they feel more knowledgeable about the current situation at a national level and are able to share this with others.

5.2.4 Strengthening and representing the voice of service users and survivors

Those who reported an improvement in their own capacity also tended to report that NSUN has helped to ensure better representation of the needs of service users and survivors. This was also something that came through from the NSUN member survey results. For many, this has been a result of better communication and connections within and across regions – the two are seen as synonymous – in terms of spreading the word about the work that is being done in this field. Moreover, there is an assumption, that as a national network, NSUN is actively putting the needs of service users and survivors out there and putting their view across to different Government departments. Examples provided to support this include its involvement with the Department of Health's consultation, advising on key issues in the mental health and social care field. One survey respondent expressed this as NSUN 'joining the dots'.

However, a few feel that NSUN still needs to do more to convince its members that it is a useful resource in order to get full approval to represent them. Generally there is a sense that there is a significant amount that NSUN could be doing within the current political and policy environment to help ensure their needs are considered. Particular issues seen to be of major national concern include:

★ transfer of responsibility for commissioning of mental health services from PCTs to GPs
★ introduction of individual care accounts
★ overhaul of the benefits system

There is a consensus that in this respect NSUN can play a valuable role in helping to ensure its members feel well-informed and to provide some reassurances that the Government is aware of how these changes will affect them. Members do feel that NSUN has influenced policy within the context of providing this representation, although more proactive work could be done to further enhance this role.

> *"[NSUN] has influenced policy. It's reactive but not proactive ...It needs to be proactive to let people know what it does and to help them in responding to things"*

5.3 WHAT IS WORKING WELL

The feedback from members suggest that NSUN is having a real impact for some in terms of building their knowledge of good practice and their confidence in sharing their work and in leading others. This has particularly been the case for those who have accessed training and have been proactive themselves in

searching the NSUN website for contacts in other areas and approaching these. For these people, their exposure to NSUN has acted as an enabler in getting them 'out there' and conversing with others, which is usually something they have wanted to do for some time but have been unsure as to where to start.

Although some members feel NSUN has been effective in building networks nationally, there have also been some real areas of concern in terms of how this can be further developed and what are seen as significant barriers that are currently preventing this from happening. These are discussed in the following section

5.4 DIFFICULTIES FACED

Some members are concerned about the amount of capacity NSUN itself has to deliver its original objectives. Comments were made about the perceived limited number of people who work at NSUN and can respond to the demands of members across England. There is an impression that only one or two members of staff are aiming to address the needs and concerns of many groups and also many individuals who need support and guidance in building up their own skills and resources. Generally the respondents spoke very highly of the staff at NSUN and the lengths to which they will go to offer that support. However, this is perceived to be a real tension for NSUN and a potential barrier to further expansion, whilst maintaining the level of service and support, if more resources are not introduced to strengthen membership-side liaison.

"The staffing level is too small to be able to deliver on a national basis.
Only 2 or 3 work there. We have 1 locally here [in our organisation]"

A small number of respondents were concerned about the extent to which NSUN really is nation-wide in its operation. This is mainly due to an impression that member numbers and networks are not that well developed in all regions. A few members commented that NSUN started off as quite 'London centric' and that the location of events tended to be in London or the South. They expressed a wish to ensure that future seminars and conferences are held further North in areas such as Sheffield and that efforts are made to use new technologies such as video conferencing to enable more to get involved.

There is also a perception from some members that NSUN initially struggled to take form and start working towards its objectives because of problems with the original management structure.

Overall though, the feedback suggests that NSUN has already achieved some success but that it has only really started making real progress in the past year.

From the member interviews undertaken there were still a few who are not yet convinced of NSUN's role and reported that they feel isolated due to being in areas where there is an absence of good, local networks. These are perhaps the members for whom there is the most to be gained by becoming part of NSUN. It may be that more hands-on work is required in these areas to target contact with existing groups and to help foster a better network locally. This is something that NSUN is known for, but not all members are convinced that this is carried out fully, mainly because of concerns over its capacity.

"As a leader of a group I'm isolated and I have no-one to share problems and ideas with"

5.5 ADDITIONALITY

Most members reported that NSUN is unique in that it is 100% user-led. Its role in attempting to connect networks across localities, regions and the country is also seen as a much needed addition to the service-user and survivor field. It is recognised by members that the service user movement is largely uncoordinated and fragmented, so NSUN's role in this is vital. Although other organisations such as MIND and Rethink also represent the user voice, these are seen by the members interviewed as being focused on a range of aims, of which user representation is just one and therefore do not have the same ability to be able to influence policy and delivery at a national level.

Those members who are positive about NSUN's achievements to date are clear that they would not have been able to progress as quickly in developing their own skills and learning about different models of user involvement if NSUN had not been created. The small number who struggled to see its impact thus far felt that there would not have been any real change to their circumstances or that of their organisations.

5.6 FURTHER DEVELOPMENT OF NSUN

The majority of members interviewed feel there is a definite demand for NSUN going forward, though only if it retains its focus on building up connections between local areas and regions. They reported that NSUN should now be focussing on strengthening and expanding its role as a hub and facilitating information sharing between groups and areas. There is a sense amongst members that NSUN is needed more now than ever in terms of enabling the sharing of good practice, supporting organisations at local level and in ensuring their voices are heard in what is now a very sensitive time of policy change for service users and survivors.

The member survey carried out by NSUN also asked what members wanted NSUN to be doing in 1-3 years' time and what they would like NSUN to be doing that it isn't doing at the moment.

Whilst there were many responses that aligned with the feedback we received during the telephone interviews regarding connecting local groups (as well as more local activity and presence), continuing to share and disseminate information and expanding the membership base, there was also a wide range of other examples given. This spanned from NSUN being active in campaigning through to organising excursions. This highlights part of the challenge that NSUN is faced with. There will be many members with their own specific needs, which in turn will translate into expectations and demands on NSUN in terms of helping to meet their needs. NSUN must remain clear about what it is there to do and what it is not – this must be clearly communicated to all members in order to manage member expectations.

5.6.1 Political and Legislative Environment

As touched on in the previous section, there are particular concerns amongst members regarding suggested and likely changes to policy, including the ways in which service-users and their carers may receive support from the state, and what that support will look like. This includes the changes in commissioning services and the review of Incapacity Benefit. However, members recognised that there are also potential opportunities in terms of the perceived willingness and aspiration of the coalition government to consult with user groups and the public more widely.

> *"The structural changes proposed in the white paper, abolishing PCTs etc and the transfer of commissioning over to GP consortia.*
> *I'm not sure how service users will be properly consulted in the consultation"*

5.6.2 Raising Awareness of NSUN

A few members suggested that a great deal is still to be done in terms of raising awareness at a local level of the role NSUN can play in allowing individuals and groups to speak to and learn from others in different areas. Again, there is an assumption that the relatively low numbers of staff at NSUN means that NSUN is unable to effectively raise awareness in all regions (and therefore sub-regions) and to make the most of its role in facilitating development within this field.

6 CONCLUSIONS AND RECOMMENDATIONS

6.1 SLOW START – BUT PICKING UP SPEED

There is little question that NSUN faced a series of issues and challenges during its initial development stages. At times these were as a result of problems that could not have reasonably been predicted and others were as a result of things which could have been avoided.

The early activity of NSUN in presenting itself to the service user movement had been perceived as insufficiently consultative and not providing enough opportunity to shape NSUN. Although this was quickly recognised and rectified by NSUN, it had the potential to severely hamper NSUN's ability to attract members. For an organisation with a core aim in relation to empowering people to be heard, and promoting the need for policy makers and others to consult with the service user movement, there should never have been the situation where their potential members perceived a lack of consultation. However, as mentioned, NSUN acted quickly to address this and begin the process of building bridges.

From our analysis of the findings it is also our conclusion that NSUN did not recruit the right person for the post of manager at the outset. This has had a dramatic effect on the progress of NSUN and where they are now, versus where they could potentially be if the right person had been in place from start. However, in the current manager NSUN now appears to have the right person for the role. She is highly regarded amongst the stakeholders we spoke with, and is seen as the driving force behind NSUN, making strong progress and steering the ship effectively.

In summary, NSUN is probably about 18-24 months behind where it ought to have been by this stage in its life. However, it is now picking up significant momentum under a motivated and capable manager.

6.2 HOSTING ARRANGEMENTS

Related to the above, there were also some challenges in relation to the hosting arrangement with Together. The issues around compliance and 'fit' with processes were not necessarily serious issues nor did they have a drastic impact on the activity of NSUN, though they did create some tension between the two organisations. The main drawback of the hosting arrangements was that many in the service user movement refused to recognise NSUN as its own organisation or recognise it as being truly user-led during the hosting period.

As much as these issues were present we need to recognise that there were also many benefits associated with the hosting arrangements and that these benefits actually outweighed the challenges and issues.

Choosing to host NSUN (rather than set up as an independent charity from day 1) was the right thing to do. Providing the new organisation with a supportive environment and established processes (albeit not all were fit for purpose for such a small organisation) gave them the support and freedom to hit the ground running and develop a solid foundation on which to build. As we discuss later, there are lessons to learn from the hosting arrangements, but in summary it was a pragmatic and effective arrangement for the early days an ambitious and innovative new project like NSUN.

6.3 REACH

Although we were not able to establish an exact figure in relation to member numbers, we can reasonably assume that the NSUN membership base totals somewhere between 800-1000 members. When the original research that led to *On Our Own Terms* was completed in 2002, the 318 local groups invited to participate had a combined membership of around 9000 service users/survivors. Consequently, we can conclude that NSUN's membership is not yet extensive enough to be representative of the movement, particularly if it is to be seen as a truly national network.

However, given the slow start and early challenges that NSUN has had, we still believe this to be an impressive member base to have achieved – and it continues to grow at pace. The job though, is far from done and continued focussed activity to continue to build the membership is needed.

We have already discussed the chicken and egg scenario relating to reach and influence. An added challenge is that users and groups may consider NSUN a 'safety net' rather than something they need to be actively involved in – all the time a user or survivor does not have a need for NSUN they may ignore it; as soon as they have a problem or need their voice to be heard, they will want it. This adds to the challenge of attracting members. However, recent and impending policy shifts and changes to public funding may change this.

We cannot emphasise enough how important reach is for NSUN, both in terms of influencing its future sustainability and to be recognised as a truly national network that encompasses the voice of service users across the country. Its member base will also dictate the overall impact that NSUN will have in terms of influencing policy, service delivery and service design at a local and national level.

We therefore make a number of recommendations about NSUN growing its membership:

NSUN needs to understand its current reach better. It needs to examine the current membership, to understand:

★ how many individuals the group members represent
★ the geographical spread of members
★ where possible, the conditions and interest groups that members represent

This would give a more accurate assessment of NSUN's current reach, not just in terms of numbers but also in terms of representativeness.

Moving forward, NSUN should use identify areas of under-representation, and target these in its efforts to grow the membership, as well as attempting to grow overall numbers.

To achieve critical mass, we recommend that NSUN needs to achieve membership numbers approaching 5000, and that those members represent a broad geographical spread.

6.4 IS THERE STILL A NEED FOR NSUN?

Our assessment is that there is still a need for a national network, and that NSUN is the most appropriate model for continuing this work. The needs that NSUN was created to address have not gone away. NSUN has made progress, but the service user movement is still fragmented and needs support to build a stronger, more united voice. In addition, recent changes to government now present new challenges for mental health service users and survivors: budget cuts, the introduction of GP commissioning and changes to the benefit system. GP commissioning could actually present opportunities for the service user movement in the medium term, but in the shorter term user groups may struggle to survive as public funding is dramatically reduced and other funding options come under pressure. NSUN has a crucial role in supporting groups to build capacity, collaborate and survive during the next year to eighteen months, and in building their readiness to capture the opportunities that might be offered by GP commissioning.

Whilst the need for NSUN remains, its funding situation is fragile too. With only two years funding left, it needs to make substantial progress against its original objectives if it is to stand a chance of securing funding for the future. Its funding bids will only be taken seriously if it can demonstrate that it *is a truly national and representative organisation* that adds value to the user movement. Our findings indicate it has made very positive progress, and is adding value in a number of different ways, but that reach and representativeness is not yet enough yet to be able to confidently make that claim. Our specific recommendations about reach, and target membership numbers, are set out in section 6.3. Our findings also indicate that further work is needed to improve connections across groups and service user organisations.

To ensure that the next two years generate the necessary further progress, NSUN should focus on the three core priorities shown in the diagram below.

Reach –
membership base

Capacity
building,
empowerment
and linkages

Influencing
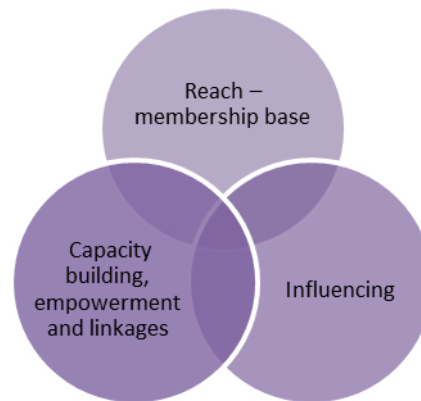
Although we would recommend that NSUN continues to identify opportunities to 'win' funding by delivering project work, it is essential that NSUN only bids for projects which align with these three priorities and contribute to NSUN's strategic objectives and direction. Otherwise, it might lead to NSUN becoming distracted by 'chasing funding', which ultimately might detract from NSUN's ability to achieve its core aims; therefore a strategic focus and approach to this is required.

6.5 FUTURE SUSTAINABILITY

In considering the future financing of NSUN, it is important to note that membership subscription is not an appropriate model for funding (even in part) a network for mental health service users. Research shows that people with mental health problems tend to experience financial disadvantage, therefore many potential members would not be in a position to pay a subscription. Consequently a subscription model not only goes against the ethos of inclusivity of NSUN, but it would represent a fragile and unreliable income source.

Although there is little doubt that NSUN is in a good position to access project work which generates income for NSUN, it is difficult to see how NSUN can continue to operate in the medium term (ie beyond its current funding period) without attracting further grant funding that enables the core activity of NSUN to be delivered. Once NSUN has further developed, and has reached a critical mass of service user membership, then it is possible that there may be other options and opportunities. However the lost time, experienced as a result of the early challenges and issues in setting up and developing NSUN, means that is not as far down the line as it should or potentially could have been.

With the likely increase in demand on charitable organisations' funding, NSUN will face stiff competition for any funding that is available – it is therefore essential that NSUN can easily articulate the added value generated by NSUN and what the funding will 'deliver'. Given that NSUN already intends to do some sustainability planning with Pilotlight, we would suggest that this work includes some scenario planning to consider the implications and impact of different scenarios such as:

★ different levels of funding available
★ different numbers of members achieved
★ likely scenarios relating to GP commissioning

Rather than relying on finding a funder for core costs, an alternative would be to build a proportion of core costs into each funded project. For example, costing for the proportion of overheads and core staffing costs that would be used in support of the project. If a core cost recovery model could be developed, then

NSUN could begin to move away from needing separate 'core funding'. We therefore recommend that NSUN develops a core cost recovery model, that will form part of the costings for any funded project.

6.6 WHAT DIFFERENCE IS NSUN MAKING?

Being part of something bigger – as the diagram below illustrates, NSUN has begun to create a coherent chain of service-user infrastructure from the very local up to the national.
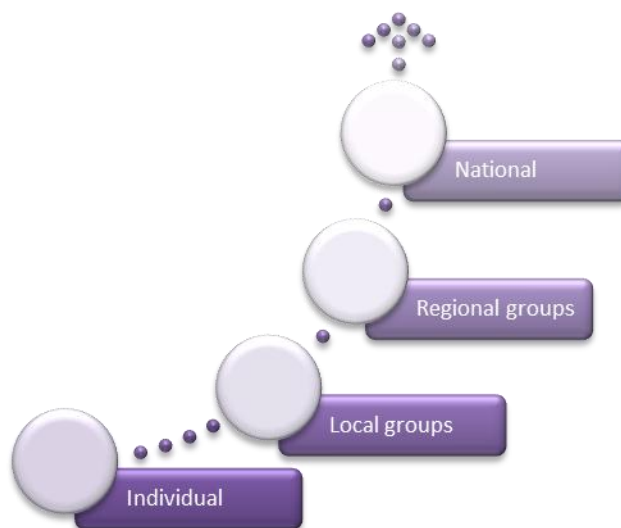
This is especially true in the regions where NSUN has supported the development and strengthening of regional networks. Members and stakeholders told us that this makes people at the local level feel that they are part of something bigger. This gives them confidence and inspires them to be involved. It also gives them somewhere to go with issues when they need/want to go further than the local arena.

Influencing service delivery and policy – NSUN has had some notable success in facilitating service users to influence service delivery and policy. Feedback from a commissioner in the north east of England described NSUN's support to the regional hub there was pivotal in increasing the extent to which service users are involved in influencing service development. At a national level, NSUN's work with NMHDU has given up to 260 users and carers a platform for influencing policy. The feedback from NMHDU and the local commissioner indicates that NSUN has created a coherent framework for service user involvement that made it easy for them to involve more users in a meaningful way.

There is an important lesson here: NSUN has a key role in removing the barriers that stop commissioners and policy makers from engaging more with the user movement. If the barriers are eliminated, it won't necessarily happen automatically, but there will be fewer legitimate excuses to avoid it.

NSUN's success in working with NMHDU is one of its notable successes. Unfortunately, NMHDU is being abolished as part of the coalition government's restructuring of national public services. This presents a major risk to NSUN, as it will need to start over with the new structures that replace NMHDU.

Capacity building and linkages – Whilst this has not been universal, NSUN has helped individuals and groups develop their capacity and confidence, and has enabled them to make contact with other like-minded groups and individuals to learn from each other and work together. Again this is most evident in the north east where the regional hub has led to greater subregional and regional collaboration, bringing people and groups together into a stronger movement.

Providing a platform rather than being a mouthpiece – NSUN has helped give service users and groups with diverse experiences a platform for having their voices heard. This aligns with the point about being part of

something bigger – NSUN does not try to speak on behalf of all service users, but offers opportunities for smaller groups' voices to be elevated to a level where they will be heard by the right people.

Bringing structure to service user engagement – We have already explained the value that NSUN has generated by offering a structured framework for service user involvement above. This cannot be underestimated – the easier it is for commissioners and policymakers to access, engage and consult with service users then the more likely it is to happen.

6.7 WHERE SHOULD NSUN BE FOCUSSING ITS EFFORTS?

As described in section 6.4, NSUN needs to focus 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
★ building capacity in the movement – capacity building at local and regional level, developing more resources to support local groups

Additional projects can be helpful in generating income and strengthening the sustainability of NSUN, but only where the projects are clearly aligned with these three core areas of business. In our research work we have seen organisations with fragile funding situations that have become distracted by 'chasing the money'; this can lead to a deviation from core aims, and a resulting loss of credibility with the organisation's core membership. NSUN needs to be vigilant in maintaining focus and avoiding this distraction.

It's important to recognise that, whilst highly skilled and committed, NSUN's core team is small.   To achieve these goals, NSUN is now in a position where it can use the passion and talents of its member base to help drive NSUN forward. NSUN should think about how is can harness the goodwill of its more active and confident members to support the following activity:

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

Technology will also be important in maximising the effectiveness of NSUN in the light of such a small staff base. Opportunities include a members' forum on the website, use of social media, video and online tutorials and video based resources. The recently redeveloped website could be a valuable asset for NSUN's capacity building work. It already contains useful and well-regarded content, and could be the conduit for a wide variety of self-service resources.

In addition, regional hubs are a powerful model for achieving NSUN's three core objectives. NSUN was always envisaged as a network of networks, and the creation of regional hubs in the other regions needs to be a priority action.

Finally, whilst many members are proactive enough to seek out contacts and linkages with other groups, some may lack confidence to do so, NSUN's capacity building role should include actively encouraging and supporting members to link up and learn from each other. In the challenging times ahead, peer support and collaboration will be essential to the survival of small, vulnerable groups.

6.8 WHAT CAN WE LEARN?

In addition to the conclusions described above, there are a number of more generic lessons that the funders and others can learn from the creation of NSUN, that could be applied when funding or developing projects with similar characteristics.

6.8.1 Hosting/independence

Hosting allows a project to get moving quickly in a supported environment. However, thought needs to be given to how the hosting is perceived externally; there is the risk of the project being seen as not truly independent, or of the host being suspected of unduly influencing the project. The benefits probably outweigh the disadvantages, but careful communication is needed to manage perceptions.

6.8.2 Staffing contingency plans

Any project with a very small staff is vulnerable to staff absence and ought to have staffing contingency plans to ensure that things don't grind to a halt if a key team member has a period of illness. However, user-led projects are particularly vulnerable, by virtue of being led by people who have been service users and may continue to be so. Their personal experiences and credibility are critical to a successful user-led project or organisation, but it would be particularly prudent to develop staffing contingency plans to enable the project to continue during a period of sickness absence. This would help build a resilient organisation.

Contingency plans might include:

★ job-sharing across key roles, to ensure cover if one of the job sharers was unwell
★ part time roles, so that whilst the whole time equivalent numbers might be small, the total staff numbers (and therefore people available to cover absence) are higher
★ allocation of lead responsibilities for trustees/board members, so that if the manager is off sick, each board member or trustee would have knowledge of specific areas of operation and could provide care-taking management of those; this would of course require trustees/board members to agree to these roles, and to have the necessary expertise in their areas of lead responsibility

6.8.3 Longer term funding

Comic Relief's and Tudor Trust's funding for NSUN was unusual in being a five year grant rather than three years. This has been particularly helpful and, realistically, for a project of national scale, five years is the minimum reasonable funding horizon. NSUN's experience shows that even a five year grant might not be enough to get to the point of sustainability. With its early difficulties, if NSUN had received a three year grant, it would have been very difficult to make the case for continued funding with the progress made by that stage; our findings indicate that substantial progress will still be needed in the next two years for NSUN to be in a stronger position to seek continuation funding.

6.8.4 Competency-based recruitment

NSUN's experience illustrates the impact of recruiting a manager without the right competencies at the outset. It also demonstrates the difference that a manager with the right competencies can make in a relatively short space of time. Competency-based recruitment is a practice used by many large corporate employers, using the following methods:

★ development of a competency framework, building upon the job description and person specification – this framework sets out in detail the skills, behaviours and experiences that the individual would need in order to demonstrate capability in a number of pre-agreed competencies
★ competency-based interviewing that seeks real-life examples from the individual's experiences, to demonstrate the individual's capabilities in each of the competencies
★ use of ability tests and exercises (eg inbox exercises) to assess competencies such as personal organisation, critical thinking, numerical reasoning, ability to prioritise

This approach takes a little more time to plan and implement than a more conventional two stage interview process plus psychometrics. It would also require the input of a specialist in competency-based recruitment. However, NSUN's experience illustrates that a little more investment at the beginning could significantly reduce the delays and challenges experienced when an organisation recruits a person with the wrong competencies. Therefore competency-based recruitment could be put to good use when recruiting managers and board members for projects and organisations such as NSUN, where the right leadership is absolutely mission critical.

6.9 IN CONCLUSION

After a difficult start, NSUN has had some notable successes in supporting service users to become more involved in the planning and development of services and policy.

There are uncertain times ahead, with radical changes to how health services are commissioned and provided in England, and an extremely challenging funding landscape. We have already described the fragile nature of many service user groups, and the challenges ahead with the deepest public spending cuts of the post-war period. NSUN's role as a knowledge, capacity and capability broker has the potential to help service user groups to improve their resilience during an uncertain period, and ready themselves for opportunities that are likely to emerge in the medium term.

NSUN needs to develop further, in order to perform this necessary support function over the next few years. It needs to further expand its membership, and continue to focus on building the capacity of service users and service user groups. More needs to be done to create linkages between service user groups and organisations.

NSUN also needs to build upon its impressive track record of influencing at a national level. One of the key organisations that NSUN has been particularly successful in influencing – NMHDU – is being abolished, and this will cut off an important route into government for NSUN. These developments will help to strengthen NSUN as a sustainable platform for ensuring that service users can make their voices heard to providers, commissioners and policymakers.

Appendix 1
Stakeholder interviews

Stakeholder	Organisation
Joyce Kavelik	WISH
Shannon O'Neil	Mind
Mark Kilbey	SE regional Hub representative
Alistair Cameron	NE regional hub representative
Jim Symington	National Mental Health Development Unit
Jane Harris	Rethink
Stephanie McKinley	South London and Maudsley NHS
Clare Helman	Together
Helen Lang	Pilotlight
Julie Jay Charles	Equalities National Council
Janice Lowe	Independent Consultant
Fiona Kerr	Mental Health Helpline Partnership
Duncan Marshal	Time to change
Dominic Walker	Together/NSUN board member
Tina Coldham	NSUN chair
Mike Tiernan	NHS (NW region)
Kathryn Hill	Mental Health Foundation
Patrick Vernon	Afiya Trust
Liz Felton	Together
Sarah Yianoullou	NSUN
Anne Beales	NSUN
Paul Johnson	County Durham PCT
	North East Mental Health Development Unit
Laura Roling	Comic Relief
Catriona Slorach	Tudor Trust
Catherine Jackson	Editor of NSUN newsletter
Peter Beresford	Shaping Our Lives
Claire Ockwell	NSUN board member
Judie-Ann Barter	Mental health Providers forum