

**A FINAL BRICK IN THE WALL?**

**A HISTORY OF  
THE NOTTINGHAM ADVOCACY GROUP**

Compiled by Marian Barnes

2007

## A Personal Statement

I first came into contact with NAG in the early 1990s when I was researching mental health service user and disabled people's organisations. NAG by then was a well established group engaged in a range of initiatives that sought the empowerment of people who lived with mental health problems. They were not unique, but had not only achieved a significant place within the mental health system in Nottingham, but were starting to have an influence on the broader development of the mental health user movement throughout the country.

Since then I have retained a distant and occasional contact. I became a member of NAG and read about what they were doing in the *Advocateur* and later *NAG MAG*, but made frequent reference to the significance of what they were doing as my work on user movements and citizen participation developed. When a group of service user researchers started to come together in Birmingham (the SURESearch Network) I and colleagues contacted Colin Gell and invited him to take part in a study of users' experiences of compulsory detention under the Mental Health Act. From there Colin became a significant figure in the development of SURESearch. It was a chance meeting with him in the corridor of the Institute of Applied Social Studies at Birmingham University that led to the idea of compiling a history of NAG. We speculated on the value of this and when I followed this up with a phone call the following day, Colin said he had already talked with colleagues and suggested that we should do this.

The importance of such a record was emphasised when I read an article published in the early 2000s which claimed that 'user involvement' in mental health services was a new phenomenon. It became even more acute when, as we will see, NAG started to face a major crisis in its history. By 2006 not only NAG, but the user movement more generally was facing a

problem faced by many other social movements: what do you do when the apparent success of your campaigning means that the ideas you are advocating are taken up by the mainstream? The answer to that is still uncertain.

This account is based on a study of historical documents, and on the memories of people who have been involved with NAG at different points during its history. It also draws on my earlier research with colleagues at the Universities of Leeds and Sheffield. Many histories can be written - they will not all be the same. What I have aimed to do in this account is to understand the significance of NAG, not only in terms of what it has meant and what it has achieved for service users and providers in Nottingham, but its broader significance in the context of the growth of the mental health user movement in the UK and internationally. I have aimed to compile an account that those who are currently active can claim as their own. It will reflect on achievements and frustrations - the value of such accounts is not only to capture 'what happened' before this is lost from the memories of those who took part, but also to provide both inspiration and learning for those engaged in similar projects. It is dedicated to all those who have played their part in improving the lives of people who live with mental health problems through their involvement in NAG, but in particular it is dedicated to Colin.

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## Twenty Years of the Nottingham Advocacy Group

2006 marked the twentieth anniversary of the Nottingham Patients Council Support Group, the group which led to the formal establishment of the Nottingham Advocacy Group. This account starts with the way in which NAG developed from its origins in the mid 1980s until the present day.

### Origins and Early Years

At the World Mental Health Conference in Brighton in 1985 visitors from Holland spoke about the development of Patients Councils in that country. Amongst those attending the conference were Ingrid Barker, from MIND, Edward Peck, then administrator to mental health services sector teams in Nottingham and Andrew Lowe from Nottinghamshire Social Services. The Dutch speakers sowed the seeds of an idea in their minds and later that year they invited Wouter van der Graaf from the Dutch Clients Union to visit Nottingham. Colin Gell met with him at the Gateway Day Hospital.

Nottinghamshire Social Services provided money to enable Wouter to spend 3 months in Nottingham in 1986 to explore the possibility of setting up a Patients' Council in Nottingham. A small steering group comprising Gary Robson from the Law Centre, John Williams from regional MIND, Audrey Mullender and Geoff Eley from Nottingham MIND, Philip Bean from the University of Loughborough, Colin Gell, Glenys Brocklebank and others constituted themselves as the Patients' Council Support Group and met to start planning this.

The first user run ward meeting took place on January 23<sup>rd</sup> 1986 at Saxondale Hospital - then the county psychiatric hospital. This was a spontaneous gathering. Members of the Patients' Council Support Group (NPCSG) had visited the wards to speak to patients about the idea of setting

up a Patients Council and this struck an immediate chord. The response was 'let's do it now!' So a meeting was set up on the spot - resulting in representations being made to hospital managers by NPCSG about the failure to provide an evening club for more than 20 minutes because the person running it turned up late. These representations achieved an immediate result and patient advocacy was on its way.

In March 1986 patients and mental health workers were invited to attend a two day conference to discuss 'Patients Taking Power'. This was the first time anything like this had happened - an event at which service users and workers met together in equal numbers to discuss how users could exert more influence over services. Some of those who attended had previous experience of political activity in other contexts, but for many this was the first time that they had taken part in any type of event where their views were sought. Colin and others who took part in this conference recalled that during the first day workers and users tended to keep to their own groups to discuss ideas separately, but on the second day they came together and there was a real sense that both groups were keen to find out how users could be involved in shaping services. Users felt that this was the first time many mental health workers had realised that service users could think about such issues and come up with suggestions that made sense.

The early contacts with Saxondale took place as preparations were being made for closure as part of the national programme to close long stay psychiatric hospitals and move patients into smaller, community based units. This provided an opportunity for the new Patients Council Support Group to work with patients to help prepare them for the move. The Mental Health Unit Manager, Philip Hogarth, provided £1000 to pay expenses associated with this and also supported the Group in making contacts with patients on the acute wards. However, not all hospital staff were supportive. In April 1986 NPCSG was banned from the hospital because a consultant psychiatrist objected to them meeting with 'his' patients. He had not been informed by hospital managers about the start of the visits.

At about the same time Wouter reached the end of his contract. He was reluctant to leave Nottingham, but the Group felt confident that they were in a position to go it alone - a judgement that proved to be entirely correct. Visits had started to Mapperley, the Nottingham city hospital, and in September 1986 the first Patients Council meeting took place there. Group members described how patients came out of the wards into the long corridor that ran along the hospital and marched along it toward the meeting room -an image reminiscent of workers downing tools in a factory and marching to trades union meetings.

In these early days the group had been supported by MIND, but by 1987 plans were being made for it to become a completely independent user run organisation. The Nottingham Advocacy Group - NAG- was launched as an independent limited company in 1987 with Audrey Mullender as the first Chair of the new organisation. It was launched with three main elements to its work.

First, it continued to act as the support group for the Patient's Council at Mapperley Hospital until this folded later in 1987 because of lack of management support. This Council was re-established in 1988 and operated hugely successfully until the hospital was closed. Secondly, NAG still provided support for patients at ward level. It also provided individual patient advocacy, usually working with service users on one-off issues of concern. And thirdly it provided a longer-term citizen advocacy service involving ongoing one to one relationships. The latter was seen to be the 'least troublesome' aspect of its work and the easiest for which to secure funding. Jenny Haywood, the first citizen advocacy co-ordinator, was appointed in 1987. The other key development at this time was that the Group moved into its first independent premises in Mansfield Road.

Information about NAG was starting to spread and by 1988 members were receiving invitations to visit other places where similar initiatives were

starting to emerge. At a national level Survivors Speak Out (SSO), also inspired by discussions that had taken place at the 1985 World Federation for Mental Health Conference, was providing a platform for both individuals and groups to lobby and demonstrate. SSO had made a particular impact through involvement with the TV programme: 'We're not Mad we're Angry.' In 1988 MINDLINK was established to ensure an independent user voice within MIND and in 1991 the UK Advocacy Network (UKAN) was established to support the growing number of local advocacy groups following a conference organised by NAG.

Locally, NAG was becoming more established with funding being obtained in 1989 for a user involvement support worker (Colin Gell) and also during this year a move to larger premises in Forest Road. Gary Robson, another of the founding members of the NPCSG, became Chair. He was described as a charismatic figure, able to communicate easily with people at all levels and his appointment was considered to increase NAG's credibility. During 1990/91 user groups were being established within Community Mental Health Teams and it was felt that the group had achieved a good balance in terms of both independence from but also credibility with service providers. Funding was obtained from national MIND and from the Mansfield Brewery to support individual advocacy and John Price was appointed to co-ordinate these services. At the same time Simon Marritt started an Information and Advice Centre at Mapperley Hospital.

### **Becoming Established**

The early 1990s was a period of positive growth for NAG. The conference held in 1991 to mark NAG's fifth year was in part a response to users feeling that they were always in a minority at MIND conferences and the creation of UKAN (with Edna Conlan from the Milton Keynes Advocacy Group as the Chair) was an indication of the growing confidence of the user movement at a national level. They were starting to be proactive in pushing the user agenda. Colin renewed contact with the Dutch users' movement that year

when he visited Holland and NAG was supporting other emergent advocacy groups in Wales, Birmingham and Lowestoft.

In 1992 the first City Wide Council took place in Nottingham. This created a forum in which issues raised by users in different services could be discussed with mental health service managers. From this came invitations to NAG to send representatives to various provider level committees (although not to join the Mental Health Trust Board). There were mixed responses amongst members to NAG's involvement in these provider and commissioner led groups and committees. Some felt they had to fight hard to be taken seriously in these forums and there was a sense in which some people felt they were being used. But overall the view was that this direct involvement was a positive indication of how far they had come in the six years since the NPCSG was first established.

1993 saw the first Mental Health Awareness Week in Nottingham. This was described as having arising out of a 'talk in a cupboard' that has continued to develop and grow and became 'part of the scenery' - now lasting for a fortnight. Mental Health Awareness Week was all about increasing understanding and reducing the fear that contributes to the stigmatisation and exclusion of people with mental health problems. To illustrate this Gladys Bombek who was involved in the first week described a conversation she had during the early planning:

.....a vicar's wife once said "what if I invite these people into my home? How would they be? And I said "well, they'll be like you, they'll have two eyes, and a nose and a mouth and two ears." You know, they think they're going to see something weird and they don't know that perhaps they'll have a nervous breakdown and start with a mental illness.

This showed NAG going beyond building relationships with mental health services and giving voice to the frustrations and fears of those using them.

With Mental Health Awareness Week they started to address the social relationships that affect the capacity of people who live with mental health problems to live their lives as they wish. One method used in this process was a 'Stress Game' designed to make the link between mental health problems and the stresses everyone feels at some stage as part of everyday life.

Another way in which NAG was looking beyond the mental health system at this time was through the development of Ecoworks. Ecoworks was the brainchild of Brian Davey, one of the early members of NAG, and was designed to develop opportunities for people living with mental health problems to engage in activities to create a more sustainable lifestyle. Much of the activity was focussed on allotments where service users and other local residents could grow food to enable an affordable healthy diet and contribute to environmentally friendly food production.

NAG had also taken ownership of a caravan (called Margaret!) on a campsite in Skegness. A survey of users had revealed the importance of opportunities to get away from the stresses of their every day lives. Many users of mental health services struggled to be able to afford a holiday. The idea was that the caravan could be rented out very cheaply by service users, their families and friends in order to enable them to take a break and relax.

By 1994/5 NAG was in receipt of funding from the district health authority; Nottinghamshire Social Services; the Mental Health Trust; joint finance; the Mental Health Foundation; a local brewery and other private firms. Whilst much of this funding was short term and fragile it was enabling NAG to support patients' councils and user groups in both hospital and community settings, to provide individual advocacy, take part in joint planning, a Purchasing for Users Group (PUG) and other planning groups, provide training for mental health workers and initiate projects such as a self assessment by users of their own needs.

John Price described the way in which he was seeking to establish the individual advocacy aspect of NAG's work during this period:

...the ground had been broken by the Patients' Council and other things. But I think it was trying to make individual advocacy, in the same way I suppose, to get that to shine in the same way as collective advocacy.....I think it was trying to work more systematically on complaints with service users that hadn't happened before. And getting some success with that along the way. But recognising the limitations, and it was a mixture of frustration and success.

Michael Worth joined NAG as a volunteer in 1994. He described the link between support offered to service users on the wards through ward meetings and the one to one support offered by John:

What we do, we pick up issues which are of general concern to people on the wards. They may range from anything from the food quality, to review procedures and that kind of thing. Whereas John does a one to one basis, this is individual advocacy with individual patients. Now they know John and often they go on the ward and say 'oh I want to see John, can you put him in touch with me and I ring John and get in touch with him. But that's John's role. He is on a one to one basis whereas ours is more of a general thing on the wards.

This everyday contact with service users in order to take immediate action to improve their experiences of services is the core of what NAG is about. It grew out of the powerlessness felt by people with mental health problems when trying to exercise some control over the services that are intended to make them feel better and too often end up adding additional problems to their lives. But as we have seen NAG's objectives extended beyond improving mental health services. Research conducted with NAG in the early 1990s identified a range of other objectives that all related to improving the lives of people with mental health problems:

- ❖ improving access to educational and employment opportunities;
- ❖ influencing public perceptions of people with mental health problems;
- ❖ establishing alliances with other groups;
- ❖ increasing the participation of people with mental health problems in both local and national politics,
- ❖ achieving rights to specified services and
- ❖ ensuring the rights of people with mental health problems are protected by anti-discrimination legislation.

At a time when 'patients' were being reconstructed as 'consumers' NAG saw people with mental health problems as citizens with contributions to make to their communities as well as rights to fair treatment within and outside the mental health system.

The Annual Report of 1995-6 was upbeat. It celebrated the 10<sup>th</sup> anniversary of the creation of the Nottingham Patients' Council Support Group and of 10 years full time unwaged work by Glenys Brocklebank. The group had seven waged staff and 24 full time or nearly full time unwaged volunteers working to support service users in a wide range of services. It was also applying to the National Lottery for funding to support a young people's advocacy development worker, was reviewing work on advocacy in residential homes and exploring the possibility of funding for other posts. John Price reported that they had achieved agreement with the Health Authority for a specification for advocacy services which meant funding was agreed on an annually renewable basis against a service specification. A second caravan came on stream to increase the number of people who could take advantage of a cheap holiday, and within the office NAG had invested in IT equipment and established an Information Centre in order to improve both its internal functioning and its services to users.

Brian Davey was welcomed back from 6 months in the former East Germany with new ideas for the development of Ecoworks. In his report he described plans to move into small-scale self-build projects, developing out of the rebuilding of the meeting hut on the allotments. He described his vision of creating a community centre which would be:

‘the meeting point where community and neighbourhood development could link up with community care as it would provide meaningful activity for long term users in a non-stigmatised setting that a wide variety of people use.’

The group held a two day 10<sup>th</sup> Anniversary conference and Colin Gell wrote of this:

Both new comers and people who have been involved for a while went away enthused to continue the fight for recognition for service users.

But he also felt that there was a worrying lack of interest from amongst mental health workers for this event and suggested that: ‘Maybe the very fact that user involvement has been around for ten years means that people now ‘take it for granted’ and have stopped working at it.’

This greater familiarity with user involvement was reflected in national developments to which NAG members were making a significant contribution. The Department of Health set up the Mental Health Task Force in the mid 1990s to support the development of mental health services nationwide and the three key national user organisations: Survivors Speak Out, UKAN and MINDLINK were all represented on this task force. Colin Gell had a substantial role in a series of regional conferences which led to the establishment of new local groups as well as stronger links between users and the Department. He also worked with the Centre for Mental Health Service Development at Kings College, University of

London to develop user involvement training in more than 60 areas where there had previously been little user group development.

### Facing Challenges

As NAG moved into its second decade it started to face a number of challenges and those who reflected back on this period described it as a very painful time. There were a number of aspects to the difficulties experienced during this period.

- The first related to the increased size and complexity of the organisation. NAG was in receipt of funding from a variety of different sources, usually linked to specific aspects of its work. Its internal financial management systems had probably not kept pace with the size and complexity of its activities and it became evident that insufficient financial control had been exercised.
- The second concerned internal organisation, management and accountability and appropriate models for this in the context of a user led organisation that was supporting an increasingly diverse range of activities.
- The third concerned the role and place of volunteers and the extent to which they felt they were trained, supported and valued for the work they did.

And underpinning much of the debate concerning these issues were differences in views about the centrality of advocacy in comparison with other aspects of NAG's work, a difference that was underpinned by different conceptions of empowerment. These issues came together in disputes about which activities should receive financial support from NAG.

Brian Davey had flagged up the more ideological aspects of these differences in his report on Ecoworks in the 95/96 Annual Report. In this he welcomed the intention to focus more of NAG's activities on young people with mental health problems, but in doing so he suggested that this would of necessity cause NAG to rethink some of its ideas about the way they worked. He reflected on the position that he had been articulating in a number of contexts and which underpinned the approach he had been developing in and through Ecoworks:

Advocacy is always to get someone else (the mental health services, the housing office, the employment services) to do something for you, or something different. Where advocacy doesn't get you any further the only solution is to get together with other people with similar problems, teach yourself and do it yourself.

The May 1997 issue of the Advocateur contained an item about a self-help group for women who self harm. This can be considered another example of 'doing it for yourself' - the article announced 'The group is run by and for women who self harm - there's not a shrink or therapist in sight! We need to build on our strengths and smash the myth that we are social misfits.' The group had been started by a woman volunteer working with NAG and she looked to NAG for funding to support the group. However, NAG was not able to fund this because the income it received was all tied to specific advocacy projects. Although NAG supported and was glad to see the development of other user led groups it was not in a position to fund them. In July 1997 the Advocateur contained a report of a meeting of the Volunteers Forum, a group that had been established within NAG to provide support and a voice for volunteer NAG workers. This reported a feeling that volunteers were insufficiently supported and valued by the group.

It was decided to hold a facilitated Management Review meeting in order to address the evidence of differences within the group and determine

how NAG should organise itself in order to take forward its work in supporting mental health service users. At this meeting the group reviewed the frustrations that had been building up but also identified its strengths to overcome these problems and take forward its work. From the management committee perspective a key frustration was that its meetings were taken up with resolving internal tensions and dealing with day-to-day management issues, rather than being able to provide a strategic steer for the development of the group.

The outcome of this, reported in the November issue of the *Advocateur* and in the 1997 Annual Report, was to create two divisions under the NAG umbrella: one would take forward the core advocacy work of NAG, whilst the other would concentrate on service developments. Each division would have its own management committee. This was intended to overcome a situation described by Jeff Cohen, the NAG Chair at the time, as one in which 'the whole has become less than the sum of its parts.' At the same time, urgent action was needed to resolve the financial crisis that had been building. The Treasurers' report for that year referred to 'unacceptable practices and irregularities' in accounting procedures that needed to be addressed and, to make matters worse, there were also cuts in the grant aid received from Nottinghamshire Social Services. The conclusion was that NAG needed 'to look towards not only making meaningful savings within our present levels of funding, but to develop financial strategies that will make us less dependent on the statutory sector.'

But in spite of these internal challenges, during this period NAG was not only continuing to provide the advocacy support that it had been developing over the previous ten years, but was also becoming involved in new initiatives. A spate of suicides amongst people in contact with mental health services led to NAG calling for an independent inquiry and a Suicide Review Group was established by Nottingham Health on which NAG was represented. NAG also became a member of the National Appropriate

Adult Network Forum - a network established amongst those who acted as supporters for people with mental health problems and with learning difficulties who were interviewed by the police. Ecoworks was developing Eco textiles and crafts projects and had secured £17,000 per year for three years from joint finance to organise weekend activities on the allotments.

Within what was becoming the advocacy sub division a patient advocacy advisory group had been set up and training provided for patient advocates. John Price's annual report indicated that the two most frequent categories of complaints pursued by advocates related to service concerns and entitlements, and mental health legislation. Patients' Council meetings were taking place regularly and if issues couldn't be resolved locally NAG was raising these with the Trust Chief Executive at the City Wide meetings. NAG was involved in various planning and stakeholder groups and Colin Gell was working with Nottingham University reviewing the content of student nurse training. NAG's involvement in the longer term approach towards improving mental health services via changing the training of mental health workers was also evident in its involvement in a consortium of voluntary sector agencies providing placement opportunities for student social workers.

Thus alongside reports of 'turmoil', of 'emotions boiling over' at committee meetings and fears of 'despondency' setting in amongst volunteers, NAG continued to do what it had been set up to do. Some years later John Price reflected on the way in which NAG's development had been affected by key individuals who came to prominence at different times and during this period there was a high turnover of people in leading roles within NAG, not least because of what obviously became quite strong interpersonal conflicts amongst group members. But throughout this tumultuous period, key individuals remained at the core and sustained their commitment to ensuring support for mental health services users in ensuring proper treatment from service providers. An agreement with

Nottingham Healthcare Trust was reached which established user involvement in all areas of the service, progress was made on a system of self-assessment, on crisis and out of hours services and user involvement in the recruitment of mental health workers had been formalised.

By 1998 a new management committee had been elected and NAG was seeking to work within its new structure. Each division had been asked to identify 'achievable' objectives. But it was clear that differences still remained. One of the NAG members who was on the management committee at the time described meetings as 'real humdingers - they could go on for hours and hours...you wouldn't get out of there until 11 o'clock at night'. A report from the service development group was published in the Annual Report as a discussion document because not all members of the group agreed with its contents. This argued that whilst advocacy was an appropriate start for the user movement, this was not the only appropriate form of user organisation and that 'the user movement will only be relevant if it is continually renewed.' The document proposed that NAG 'as it is now' could not manage all the individual projects and initiatives under its umbrella and argued that individual projects should be managed separately. The outcome of this was that in 1999 Ecoworks, which had always been seen by both Brian Davey and others to have a somewhat arms length relationship with NAG, finally broke away and became a separate organisation.

### **Into the New Millenium**

As the millennium drew to a close and fears about the millennium bug affected NAG as well as much larger organisations, the group was seeking to recover from what had been an emotionally difficult and bruising time. The internal difficulties had affected funders' confidence in the group and budget cutbacks led, amongst other things, to a move out of the Forest Road offices into the cheaper accommodation of the International Community Centre. A number of volunteers had left (although a core of

long-standing volunteers remained) and NAG was considering strategies to recruit new volunteers with a range of skills and experience to bring to the group. Regular staff meetings were taking place and action was being taken to improve internal communication, group supervision and training. Alongside reflections on the difficulties that NAG had been going through people were also reminding themselves and reflecting on their achievements which included:

- Planning and monitoring of self-assessment.
- Progress in developing a crisis house and helpline.
- Involvement in interviewing and recruiting mental health workers.
- Consultation on patient partnership.
- Advising the school of nursing about nurse training.
- Consultation on the review of the Mental Health Act.
- Involvement in service quality questionnaire survey.

And many more.

They were also setting out future plans and objectives which would see NAG responding to key developments within the health services, such as establishing advocacy within primary care, strengthening their links with groups they had been less successful in including within NAG - such as young people and people from minority ethnic groups, and pursuing new issues such as advanced directives and mental health and homelessness.

The 1990-2000 Annual Report recorded the conclusion of a formal advocacy agreement between NAG and the Nottingham Healthcare Trust, which was considered to reflect and codify good relationships and good practices that had been developing over a number of years. In his report John Price struck an optimistic note: 'There are signs that NAG could emerge renewed in its commitment to successfully providing advocacy services in a changing climate and against a much more secure and business-like organisation.'

By 2001/2 there was evidence of NAG entering a new phase of its life. A new post of 'Co-Ordinator and Business Development Worker' was created and Mervyn Goring, who first came across NAG in the early 1990s when he was working for a housing association and was convinced by the advocacy model that they were using, was appointed to this post. Alongside the continuing development of relationships with service providers to offer advocacy in an increasing range of settings and contexts, NAG was also looking to develop its relationships with the business and voluntary sector and seeking ways of ensuring better financial viability for its activities. For example, 'Experts by Experience' - a pilot for a regional service for people considered to have personality disorder, was being set up as a not for profit limited company and Nag Mag - successor to the Advocateur was being re-launched to become income generating. The management committee was also developing a risk management strategy.

In 2004 many of the activities and issues in which NAG was involved remained familiar:

- They were onto their third caravan to provide cheap holidays (focussing in particular on single parents).
- The City Wide Patients Council continued to meet and membership had gone up - although the amalgamation of Trusts had created what was considered to be a large and unwieldy organisation which did not respond well to users.
- Mental Health Awareness week had become a fortnight and continued as a vibrant creative annual event with local media, arts, city council, health promotion and schools involvement.
- The Advocacy Agreement with the Trust was renewed in 2003.
- The way in which services are provided on acute wards was an enduring issue, but NAG continued to take up issues and could point to improvements (such as air conditioning when the weather is hot), which had resulted from their interventions.

- There were still too many service users who didn't know about patients councils and funding from the NIMHE was being used to provide training for service users to get involved.

As it had throughout its history, NAG was responding to developments within the NHS - the key ones being the major re-organisation to Primary Care Trusts which had fractured relationships established through the Purchasing for Users Group, and which had led to the development of sector based user forums which were considered to be the main focus for strategic level relationships in future, and in 2004 the amalgamation of Trusts to create the county wide Nottinghamshire Health Care Trust. NAG maintained its links with the NHS beyond Nottingham via NIMHE East Midlands and it was part of a Nottinghamshire wide advocacy forum.

And it was continuing to develop special projects. Experts by Experience was providing training opportunities in ICT and advocacy and was on its way to becoming self-funding. There was no formal agreement between this group and NAG, but the link was maintained though Simon Marritt acting as company secretary to them. NSURE was set up as a group of service users who were interested in influencing mental health services via involvement in research. NAG had also been involved in developing the STAR project, a supported housing initiative where they were providing advocacy. NAG was also providing the advocacy service for a new Personality Disorder Service run by the Trust.

## **New Challenges**

This was the situation when I met a number of NAG activists in 2004 at the start of my work compiling this history. But by 2006 when I went back to meet people to update the material for this history things were very different. Towards the end of 2005 the advocacy contract that NAG had held came up for re-tendering. Simon described preparing a bid for this as a long process in which everyone was involved and which resulted in a tender that

the group were happy with. However, they were unsuccessful and the contract went to an organisation called 'Speaking Up' which provided advocacy in a number of other parts of the country. NAG had bid to continue to provide mental health advocacy in Nottingham. Speaking Up were prepared to offer a generic advocacy service (including for people with learning difficulties) and to offer a county wide service covering the entire Trust area.

Because NAG had previously successfully argued to have the advocacy contract for the STAR project included in the overall contract this meant they lost this service as well. By mid 2006 the only advocacy contract that remained with NAG was for the personality disorder service. The loss of the contract for an advocacy service that they had developed was devastating for NAG. It meant most of their income disappeared and were only able to employ one advocate. Advocates who used to work for NAG went to work for Speaking Up and, according to Simon, found their wages reduced as the organisation realised it was not able to offer the service within the budget they had set. The remaining personality disorder contract continued to provide on costs, cover some administration, and pay the rent on the current office, but the Manager's post was likely to disappear. In 2006 NAG's income was as low as it has ever been.

The pessimism that resulted from losing this contract has affected other aspects of their work. The situation elsewhere was described as 'death by inactivity'. Whilst the City Wide Council continues to meet monthly, it is no longer the vibrant meeting it once was. Whereas the Trust Chief Executive used to attend regularly, NAG members said they are now lucky if anyone from the Trust or from social services turns up. The remaining NAG volunteers still offer collective advocacy through patients' council meetings, but there is no funding to pay volunteers' expenses. There were jokes that some volunteers could use their bus passes, but this demonstrates the fact that the remaining NAG volunteers are those who have worked with the

group since its inception or very soon after. They are getting older and NAG has been unable to recruit younger service users to act as volunteers.

Whilst not part of the relationship between NAG and the Trust, the caravan project was also coming to an end and the caravans were being sold. Simon described this as a natural process as fewer people were using them, but this contributed to a sense that NAG had reached a point where new ideas and new initiatives were necessary if it was going to continue into its third decade.

The consequences of these developments will be considered later in this history, but we need to understand more about the significance of NAG for participants and for relationships with mental health services than can be captured in a chronological account of its development.

## 2. Individual Stories of NAG

The story of NAG cannot be complete without understanding both what contribution has been made by the many individuals who have been part of the group over the years, but also what involvement in NAG has meant to them.

The impact of involvement on those who become active in service user organisations was one of the themes of the research I undertook with colleagues in the early 1990s which looked at NAG, two other mental health service user groups and three disabled people's groups<sup>1</sup>. These are some of the things that NAG members we interviewed then told us about what being involved in NAG had meant to them:

In some ways it turned out to be a positive step for me. It changed my life around from something that was killing me, virtually, to something that I finally got some kind of reward in.

It's given me a life and without it I wouldn't have dreamed of doing half the things I do now. It's given me confidence, assurance....I get up now and speak at a conference quite happily. A few years ago I would have no more done that than fly!

There's quite a few that have come here and when they came they wouldn't say boo to a goose. They've been here a bit, you can't shut them up - which is what we want to hear!

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<sup>1</sup> More details of this research can be found in Marian Barnes and Polly Shardlow (1996) 'identity Crisis: Mental Health user groups and the 'problem of identity' in Colin Barnes and Geof Mercer (eds) *Exploring the Divide. Illness and Disability*, Leeds, The Disability Press., and in 'Unequal Partners: User Groups and Community care' published by the Policy Press, 1999.

I believe in 3,4,5 years time maybe....that will give me a chance then as an individual to join the mental health service as a professional, and I'll be able to take my experience forward with me

Interviews with a small number of people involved in some way with NAG when I was compiling this history demonstrate more about how they came to become involved in NAG and what this has meant to them. It is not possible to tell all the individual stories of those who have made key contributions to NAG over the years and other stories may well offer different accounts of what it has been like to work with NAG - as volunteer or paid worker. But let us hear from six people to get some sense of what the 'NAG experience' has meant to them. I spoke to the first four in 2004 when they were still positive about the future. Simon and Gladys talked to me in 2006 and their stories reflect the greater pessimism at that time.

**Michael Worth** is a longstanding volunteer with NAG. He first became involved in 1994 after becoming unable to work following long periods in hospital. He inquired about opportunities for voluntary work within the mental health system because he did not want to end up doing nothing and he was told about NAG by staff at the day hospital he attended. He joined NAG and started going onto the wards to support ward meetings and also attended the City Wide Council as a user representative from the day hospital. Over the 10 years in which he had been involved up to 2004 he had taken on more roles: he increasingly became involved in various committees and groups within the Trust, became treasurer of Mental Health Awareness Week, secretary of the City Wide Council and in 2004 was Vice Chair of NAG. He talked of what had been achieved in terms of service improvements but also how long it can take to achieve quite small changes.

He reflected on some of the changes that had taken place over the years. When he first started there were a large number of volunteers who used to meet regularly to share what they had learnt from their contacts with

service users. Now the number of volunteers is much smaller although in 2004 he still described the experience of working with NAG as being part of a team. He thought fewer people were prepared to spend long periods working in a voluntary capacity as they wanted to get paid jobs, but he said he had never had any problem with the distinction between paid and volunteer workers within NAG - 'we are just working as a team.' He talked about the distressing period in the late 90s and wondered why he had not left at that time. The answer is perhaps to be found in what involvement in NAG means to him:

If I didn't do this I would be adrift. I would have nothing to do. I enjoy doing it. I enjoy doing it because I am working with people who are ill and I am still a service user myself. But I am a long way down the road from where they are. And you know it's nice to be able to work in that field and think you are contributing to someone's recovery in a way. Although it's a very small way, I mean it takes a long time to get anything done, but I enjoy doing it.

For Michael this sense of quiet achievement is worth spending virtually a full working week with little pay other than an allowance for attending some Trust meetings.

Kim's first contact with NAG was when she needed an advocate to support her through a problem with her GP. John Price helped her with that, but beyond this she said '....when I came in [to the office in Forest Road], the environment was so friendly and welcoming that I asked questions and spoke to Colin...I was asking questions and wanted to know more, and then eventually started doing some voluntary work for them.' Her early experience of how she got into volunteering with NAG reinforced Michael's view of the teamwork which has characterised the group:

....people would say to you, 'oh, while you're here pick up the phone', you know what I mean. And before you know it, and even though

you're really nervous about doing it, you're in it. It's that sort of environment when you walk in, it still is now. It's sort of whoever's there is part of the team immediately. It's the same - if the phone was ringing and we were all on the phones I'm sure you'd pick it up!

Feeling she was providing a service made Kim feel good - particularly as she had not been working for over 4 years. She became an advocate and joined the management committee. In spite of the difficulties during the late 1990s she was determined to stick with the group - she was committed to the services being provided and to the people she was working with. She went on to join in with the Patients Council Support Group and became a volunteer on hospital wards and in a day centre.

She described the differences between meetings in those different contexts. On the acute wards there was a turnover of patients so they never knew who they would see when they arrived on a ward to hold a meeting: '...it was just me going round introducing myself to everybody, trying to get people excited enough to attend a meeting. We used to have very good meetings but you'd never know how it would go because you didn't know who was going to be there or what was going to be brought up.' Many of the issues came up time and time again and Kim talked of the frustration she experienced because of the length of time it took to achieve change. But she thought it was often easier to achieve results on people's individual issues: about medication, the way people were treated by staff, attacks from other patients and issues to do with visitors, for example, than it was to achieve more general changes in the quality of mental health services. She was convinced both from her own personal experience and her subsequent experience as an advocate that it makes a real difference to have an advocate to ensure that people are listened to.

In the day centre people attended for a long period so it was much easier to get to know service users in that context. The focus for discussion in day centre meetings tended to include broader issues that reflected NAG's

position in national debates about mental health services and policies, as well as its concern to improve the day-to-day experiences of service users.

Following her experience as a volunteer, Kim eventually became a paid advocate in 2002 providing advocacy support in a core and cluster partnership between the health services, housing and NAG, and in a supported housing project. The core and cluster project is an example of an initiative where NAG was involved from the start in designing the service to include a dedicated advocacy service. NAG was a partner in the service but Kim said her role was clearly different from the rest of the staff and service users were confident that she was in a position to take up issues on their behalf. Her direct involvement in the service also enabled her to get to know what was going on behind the scenes - it was harder for staff to hide what was going on.

Kim talked of what her involvement in NAG means to her:

It is supporting people so that they're heard, and to do that is just really fulfilling. That's stage one and if you see that something has changed because of that, that's great. So one it's just nice for people to be heard and I love that. I love putting that across. And then when things actually change for that person, you get terrific satisfaction.....

[It's been] huge for my own personal self-esteem. I've started very small and suddenly realised that I was capable of a bit more and a bit more and a bit more, and now that I'm working full-time it's just lovely, it really is.

She also said: 'I know that I'm going to get all the support here and people will help me all they can - stand in if they can, or whatever, but at the end of the day I take responsibility for doing the job.' This sense of being able to take on responsibilities in a supportive environment is a crucial way in which user/survivor groups can not only give service users a voice,

but also model the supportive relationships which can enable people who experience mental health problems to move into or back into employment.

One of the longest standing paid workers with NAG was **John Price** who joined NAG as Patient Advocate in 1992. John had been a service user since the mid 70s and had been actively involved in MIND, MINDLINK and the Manic Depression Fellowship. He had also studied law and had a long-standing interest in rights issues. He said that when he saw the advert for the post of Patient Advocate with NAG this seemed an ideal opportunity for him.

He described how the role of Patient Advocate developed from the early days where the emphasis was very much on working on the wards of the old psychiatric hospital in order to deal with mainly short term issues, to expansion into advocacy support for people in community settings where the focus was on enabling service users to be involved in their care plans and reviews. Whilst the locations within which advocacy needed to be provided became more various and diffuse as the old psychiatric hospitals closed down and new forms of services were developed, the fundamental idea of patient advocacy that had been introduced from the Dutch context remained the same. This was an advocate as a partisan person whose function was to support users' rights and entitlements and support people to express their opinions when they found it difficult to do so. New ways of applying this had to be developed as services became more dispersed and this necessitated new ways of working, but did not decrease the need for the service.

John also talked about what it was like for him to work with NAG. He acknowledged that he had missed the 'initial burst of activity' that took place during the early days but spoke of a very positive experience with a lot of support for his role within NAG and with allies beyond the group. He reinforced Kim's experience of being in a supportive working environment:

From my point of view, working within a service user organisation.....it was a complete turnaround to the type of employment experience I had been used to...compared to my previous employment, you know where I felt, had had quite difficult periods and err felt very unsupported and that other people didn't know quite how to - within a large organisation, how to react to that. Whereas with NAG it's - I think it did my mental health a lot of good.

John talked about the significance of his own experiences of mental health problems underpinning his commitment to his job over the 10 years he acted as Patient Advocate (he returned to NAG in 2004, after a two year break):

I think I do have a very strong degree of commitment to mental health service users, not just the rights side of it, the personal experience of what it is to be a service user. And how you survive things and how you do or don't get the right sort of help. And out of the fact that I have obviously had my own problems on and off along the way, but the fact that my family had mental health problems as well. It's a strong thing for me and I think that's one of the sustaining things .... A strong belief in advocacy and a strong belief in a user organisation that provides advocacy services.....I think the really exciting thing was translating a theoretical model of advocacy into practice. But you know it's been sort of adapting that along the way and obviously the uniqueness of every person you're working with.....

This commitment to ensuring that every solution was right for that particular individual and was worked out with them meant that, in spite of the fact that many of the problems he dealt with were similar, the job never became routine. John's departure in 2002 was a personal one to move up to Sheffield when his father became very ill. Whilst he was there he worked in a non-user run advocacy project and said he missed the particular

character of a user run organisation: 'both on a personal basis but also the fact that I think from my point of view as a mental health service user it's a political issue, I think that by and large advocacy should be under the control of service users and service user organisations.' So his decision to return to work with NAG, even though it involved a long commute, was one he was happy with - 'it feels good to be back' and in 2004 he was excited about the potential of new projects that were being developed and new ideas that were contributing to those developments. John had left Nottingham by 2006 because his commitment to user-led advocacy meant that he did not want to work with the organisation that took over when NAG lost the contract.

Summing up his experience of working with NAG and what it had meant for him John reflected on the rare opportunity this had provided for him to be involved in something that brought together his personal commitments and experiences with the opportunity to develop an advocacy service capable of generating change. At a personal level he reflected on the way in which it had enabled him to develop confidence and skills as well as on the impact of the solidarity he experienced working with other colleagues in NAG - 'a sense of identification - quite a strong bond.' He located this sense of solidarity in the experience of 'pretty much being pushed up to the edge' that is hard for those who have not been to the edge to understand.

**Mervyn Goring** joined NAG rather later than the others. He described himself as having been a supporter of NAG 'from the outside' whilst he was working for a housing association which provided supported housing for people who had used mental health services, including those who had been in high secure facilities. His experience of the way in which people were treated in the mental health system convinced him of the necessity of advocacy. In the late 1990s he had started a co-operative mental health centre with NAG and health promotion and supported another home care co-operative specialising in mental health. He had contact with Brian Hoser and Brian Davey, both involved in NAG at different times, and with others

with critical views of mental health services and mental health laws. He had also started to study psychology at university but became disillusioned with the lack of a strong evidence base for the way in which mental health services are provided and so he did not continue.

He became directly involved with NAG in the late 1990s when tensions were at their highest and decided he could make a contribution to the re-organisation that was being discussed, drawing on his previous experience in business. He felt the organisation needed to be better managed and to have secure financial and other systems to ensure that no one could come in and take it over, but he also recognised that the core business of providing advocacy services was continuing effectively. He talked about the ideological differences that had also been part of the conflicts within NAG, suggesting that he did not see the different positions that had been taken as constituting 'either or' positions in terms of what an organisation like NAG should be doing. The key thing for him was that NAG should 'challenge the system' because of the bad times people have within it.

Mervyn's role as a manager in NAG was itself a challenge for some of those in the group. He thought that people both wanted things to change and were also terrified of change and sceptical of introducing more managerial control within the group. But in spite of their scepticism Mervyn's experience of the staff was that they were 'unstintingly helpful.' His focus was not only on internal changes, but on relationships with the Trust to ensure the continuation of commissioning of advocacy services. He knew they had to raise funds and said they fought hard to get a 3 year contract.

He also sought to change the relationship between NAG and mental health services by establishing Experts by Experience - a co-operative based on the principle of Time Banks that provides a means through which service users (and others, including refugees and young people) can be paid through training opportunities for their expertise. He is highly committed to this way of working and talked at length about the way in which this had helped

people develop skills, promote themselves to potential employers and address aspects of their emotional lives that were difficult for them. He related this to his own experiences, which had included severe alcohol dependency and what he described as 'emotional retardation' following his use of mental health services.

Mervyn also spoke directly of what being involved with NAG meant to him:

Well it's refreshing to know in this troubled world, that there are people committed to speaking up for those who can't themselves. And that is not because of any intellectual or organic incapacity. It's because in plain English, they are having an unjust service.....I am able to make a difference, I can inform other people who will listen to me.

He cited the number of people who had worked with NAG in a voluntary capacity and subsequently gone on to get paid jobs as evidence of the success of advocacy: 'it works, it works as a principle and it also works as a supporting network.' For him there was still much to do: 'that's why I'm still with it all, because it's unfinished business' and his strong awareness of the injustices people experience and the fragility of the circumstances of many of those who use mental health services continued to inspire him to seek new opportunities within NAG. But he also sought to continue to improve the situation of NAG itself, moving away from a situation in which what they did was dependent on people volunteering their time, to a situation in which the organisation was taken sufficiently seriously to be funded seriously.

I spoke to **Gladys Bombek**, one of the earliest volunteers with NAG, in August 2006. She was thus able to reflect on virtually 20 years of involvement with the group, including the impact of losing the contract. She said she had only got into user involvement after her she thought her working life was over, but it had become a very important part of her life.

Gladys was a patient at the Stonebridge day centre when Colin started running meetings there. He asked for volunteers to attend the City Wide Council and got no response. At the end of the meeting she said he put his hand on her arm, and, mistaking her tendency to shake as indication of support said 'you look as if you're interested, why don't you do it.'!

Gladys said she was very low at the time and dropping into the NAG office was somewhere to go rather than simply wandering round the shops. She used to watch Colin and the others working, then gradually started to do things - starting with washing the cups - 'no-one washes the cups'. She started going with Simon to sector team meetings. She said she lost weight because they walked everywhere. She also started to visit residential homes and became very supportive of what they were trying to do.

When Gladys got onto the Local Implementation Team [responsible for implementing the provisions of the National Service Framework] she found herself at meetings with doctors and frightened to open her mouth. She said she 'talked proper Nottingham'. But eventually her anger and sense of injustice meant she overcame her fear of speaking out. One instance of this was during a meeting she attended with a NAG colleague in Liverpool when a man questioned the existence of a group only for women service users. She was angry at this and said to her colleague - 'I'll speak to this one!'

As the Stonebridge user representative she went to a meeting with staff once a month. Whilst she described it as 'a bit unnerving' to meet staff including her own psychiatrist in this context, her confidence gradually increased and eventually she realised they were asking her for information about what was going on - one of the doctors said to her 'you're our messenger here!' From here she got involved in running ward meetings and for three years she has run ward meetings at the Wells Road Centre (a small hospital that was part of the replacement for Mapperley), including on the forensic ward there. When the advocacy service on the forensic ward was taken over by MACA she fought to maintain the Patients' Council in its own right.

Gladys recalled good times during the period that NAG was in the Forest Road offices. She and other volunteers would go into the office on Fridays and this was an opportunity not only to learn how things were run, but to meet up with others and have a laugh together. She said she missed Colin telling off her and Glenys for giggling when he was writing his reports. Like others Gladys described her involvement in NAG as having made a real difference to her life as well as enabling her to help make a difference to others' lives. 'Being involved makes me feel good and feel needed' she said.

She gave examples of the circumstances of service users that motivated her to support them and speak out on their behalf. She spoke of a woman who had been in the hospital for 6 months and who had no family who said how sad she felt when other patients had visitors who brought them presents. Gladys always makes sure she takes in cakes for patients' meetings as an indication that she thinks of them. She also talked about a man on a section of the Mental Health Act who was recalled from leave by the Home Office and had to spend another six months in the hospital. She said he might have done something horrible but she still felt really sorry for him because she knew how desperate he had been to demonstrate he was fit for discharge - 'that's what keeps me going.' So, in spite of expressing a number of concerns about the current state of NAG, she said she would carry on 'until they chuck me out.'

Her daughter also became involved with NAG after she was made redundant by the civil service. At one point she was Chair of NAG. She then got a paid job working in an information service run by NAG in the Personality Disorder service.

When I had interviewed her for the research in the early 1990s Gladys had described her encounter with a vicar's wife who was uncertain whether to get involved in Mental Health Awareness Week. Her disenchantment with the response of church members to people with mental health problems was still evident in 2006. She said she had never got involved in church groups as she had been upset by the comments made about 'daft people'. The sense of user groups as safe spaces in which those who have used mental health

services can be confident that others will understand them is a powerful theme running through all the stories told here and elsewhere.

However, recent changes had left Gladys feeling much more disconnected from NAG than had previously been the case. She said she referred to herself as working for the Patients' Council rather than for NAG. Her work is very much focused on the wards and she said she rarely goes in to the office. Paid workers do not come and visit the wards so there is little sense that volunteers are being supported and their work celebrated. There are no longer regular meetings for volunteers and this means she and other volunteers feel rather left out from decision making - she is obviously rather hurt about this. She said the only time everyone gets together is at the monthly City Wide Council meeting. It was worrying to hear that neither she nor her daughter felt able to express their views about the way in which NAG was developing. Her recent experience has been of the original collective advocacy that takes place through patients' council meetings on the wards being sidelined as NAG became involved in new projects like the STAR project. But this could change following the loss of the advocacy contract which has left the collective advocacy and the personality disorder work as the only regular activity in which NAG is involved.

Gladys spoke very proudly about have been nominated and receiving an 'Oscar', introduced to reward the achievements of staff working for the Trust. She was nominated by a manager in recognition for the work that she had done with patients and making connections across the forensic and acute services. The situation she described on the wards, with patients in some cases spending years on acute wards that were not designed to be long stay accommodation, is a reminder of the importance and value of the day to day support that people working with and through NAG can continue to offer.

By 2006 Simon Marritt had been involved with NAG for 16 years. He started out as volunteer in much the same way as Gladys, but he had also worked in a paid capacity for NAG - at first in administrative roles and then on collective advocacy, and recruiting, training and supporting volunteers. He

has also acted in an unpaid capacity as the NAG company secretary for about 10 years.

Simon described the way in which he learnt about what advocacy could offer by going with Colin to visit services and gradually took on some of the work Colin had been doing as he took on other roles beyond Nottingham. Simon had previously worked as a hairdresser, but had been ill for 20 years and his agoraphobia had meant he had become rather isolated. NAG was a very different environment from that which he had been used to. His experience of NAG in the early days reflected Gladys's description of a lively place with lots of people around, but although Simon experienced it as very supportive he was also aware of different factions and a high level of conflict. Because he had an administrative role he felt that he was perceived as being quite powerful and thus was under attack from those who wanted more power within the group. He observed people who he had encouraged to join up as volunteers trying to 'take over'. But by this time he was highly committed and was not prepared for others to 'take over the organization and ruin it.'

Because of his role in recruiting and supporting volunteers he has had a key role in introducing those who have subsequently gone on to take up paid jobs with NAG: including Kim and Mervyn. He has enjoyed providing training and talked of the way in which he was able to use his own experience to design training in a way that suited others who also had experience of mental health difficulties. He described his approach as highly interactive and based on a collective ethos also evident in collective advocacy.

Simon said he had been involved in the full range of activities that NAG supported during the course of his time working with them. He prefers working on collective advocacy to one to one support, but he has done some individual advocacy. He really enjoys developmental work and has been involved in setting up a number of projects, including the caravan project, Mental Health Awareness Week and Experts by Experience. Because of his interest in developmental work Simon was thinking about and planning potential new developments that would give NAG a future. Central to these

was a proposal to develop a series of themed conferences and events as a source of income, to generate enthusiasm amongst both current and potential future members, and as a means of exploring more widely current views of mental health services.

Like others, Simon's involvement with NAG had been the source of new skills, confidence and commitments. Speaking at conferences, chairing meetings, negotiating with service providers and managing accounts were all things he had learnt and that he put down to the confidence to try things that had come through his involvement in NAG. Prior to NAG he described himself as having been 'in the wilderness' for 20 years - 'NAG helped me get my life back together', he said. Speaking in September 2006 he talked of his sadness at the uncertain future NAG was facing, but he also felt he was ready for someone to take over the 'burden' of keeping NAG going. When NAG lost the advocacy contract he had briefly gone to work for Speaking Up. He did not enjoy this experience, but was also aware of a sense of relief at not having the responsibility for maintaining and developing the organization. His sense that it is time for others to take on responsibility for NAG's future development suggests that getting new blood in will be essential if the group is to survive.

### 3. NAG and the User Movement

In a conversation late in 2005 Colin Gell reflected on NAG and the way in which the mental health user movement had developed over the previous 20 years. He thought that the influence and support of Dutch colleagues had been important to add credibility and confidence that user involvement in services and user self-organisation could be successful. But once the group was established it not only developed rapidly within Nottingham but also was quickly being called on to offer advice and support to other groups that were developing in different parts of the country. Peter Campbell, who was involved in establishing the Camden Mental Health Consortium (which still exists) and was a founder member of Survivors Speak Out, characterised those early years of the user movement in England and Wales as a period when:

As there were so few people involved, people might be involved in a number of groups. It was likely that you would know many/most of the activists personally. This was also a pioneering period when people from SSO and NAG and some other groups would go out to meetings around the country to spread the word. Local groups often grew out of these meetings and were supported by NAG and SSO etc within our very limited means.

Reflecting on the user movement as a whole at that time Peter spoke of the background of many of those involved in radical campaigning organisations: the Mental Patients Union, Campaign Against Psychiatric Oppression, British Network for Alternatives to Psychiatry and the confrontational approach that was necessary to secure the right to name themselves and to speak out against discrimination and poor treatment. Challenging the use of terms like 'the mentally ill' and 'schizophrenics' was a constant battle, as was establishing the credibility of service users in speaking out about their

experiences. In this context the local success of NAG in securing a voice with service providers marked a considerable shift.

NAG's role in the establishment of UKAN - the UK Advocacy Network, was crucial. The experience in Nottingham enabled members to provide leadership, support and skills development. UKAN remains the only national user-led advocacy support organisation and it was established in Sheffield in a deliberate move to ensure user controlled advocacy developed throughout the country, not just in London. It continues to offer training and support to local advocacy groups.

NAG was able to support the development of other groups because it became locally embedded as a provider of advocacy services early on. There was a sense that the local service culture was more supportive than in other places and that Nottingham prided itself on the progressive nature of its mental health services. It may have been that starting with the collective advocacy of patients councils and then the city wide group was seen as less threatening than individual advocacy which came later in the groups' development. But it was able to secure funding for the services it provided and this required it to establish itself organisationally in a way that other groups may not have needed to do. Peter Campbell said:

I think between 1986 and 1992/3 say, NAG was hugely important nationally as it was THE mental health advocacy organisation - pioneering, promoting, training etc. around the country. It was the model advocacy service and I know many people who were setting up projects or who went on to set up projects went to Nottingham to see how it was done. So in those early 5 or 6 years NAG was invaluable.

For Colin the opportunity to enable individual users of mental health services to have a say about their treatment and about what happens to them remains at the core of the user movement. The fact that it is no longer acceptable to refuse to listen to an advocate is evidence of the

movement's success. Service users are generally more assertive and, whilst other factors such as the consumer movement have had an impact on that, NAG and other groups have played an important part in enabling those who were too often told that they 'lacked insight' to develop the confidence to speak out.

Peter's observation about the significance of language is also important here. Elsewhere I wrote:

One of the most fundamental objectives of user groups is to claim the right to self definition for those people whose identity and 'problems' have been defined by professionals. Reclaiming the right to define themselves and their problems is a prerequisite for attaining other objectives. (In Barnes, M and Shardlow, P (1996) 'Identity crisis? Mental Health User Groups and the 'problem' of identity", in C Barnes and G Mercer (eds) *Exploring the Divide: Illness and Disability*, Leeds, The Disability Press.)

As long as service users were defined by their diagnosis it was hard to recognise them as credible participants in planning and evaluating services, and making treatment decisions. Colin described a 'golden moment' early in the life of NAG when a service manager sat down with a man who had been a long stay patient at Mapperley Hospital and went through proposals for the hospital closure to ask him what he thought. Another example he cited was of another man who had been on an acute ward for a long time and whose consultant threatened to section him under the Mental Health Act if he went out of the hospital. NAG took up his case and it was agreed he could leave the hospital. He went on to write many books of poetry, to take part in conferences and had not been in hospital for many years. At a time when user involvement in planning and service delivery has become official policy it is important to understand how far we have come in terms of challenging professional dominance and control.

But as well as supporting individuals locally the involvement of NAG alongside other groups at national level has been crucial to securing

influence on the broad direction of mental health service development. As Colin said “We’d have been shown the door at Richmond House (Department of Health headquarters) if we had just come from Nottingham.” During the second half of the 1980s and early 90s Survivors Speak Out, UKAN and MINDLINK were all involved in campaigning and other umbrella groups, such as the Hearing Voices network, developed in an atmosphere that was increasingly supportive of user organisations.

Within Nottingham service users were gaining confidence to develop a range of activities. In chapter 1 I referred to a self-harm group that sought support and funding from NAG. Perhaps because of its success groups such as this looked to NAG for funding that it was not able to provide. All the funding the group received was linked to specific activities and whilst it was able to offer the use of premises for meetings it was not a source of funding for the development of other groups. The relationship between NAG as whole and Ecoworks was never entirely comfortable. The origins of NAG were in a commitment to enabling service users to have a voice within the mental health system and this developed through an increasingly diverse range of individual and collective advocacy initiatives. Ecoworks looked beyond the mental health system to the social, economic and political factors that disempower people who live with mental distress and others who are ‘different’. Brian Davey’s base within NAG enabled him to pursue his ideas and eventually establish Ecoworks - which went on to be successful in generating funding in its own right, but neither he nor others in the group felt that the two initiatives belonged together.

Although NAG has never been very successful in encouraging black service users to work within the group, they have been supportive of the development of other groups of black service users and Colin was instrumental in supporting carers to develop their own group.

This experience in Nottingham reflects the diversity of the way in which the mental health user movement has developed. Groups which can be

considered to constitute part of a broader movement have developed around shared experiences: such as of self harm, of hearing voices, of living with manic depression; amongst those who share identities other than that of mental distress in relation to gender, ethnicity and sexuality; as well as those who organise on a local basis and focus their action on mental health services. Some groups prioritise offering services - not only advocacy but drop in, crisis and support services, whilst others pursue their objectives through training, research and consultancy. Mad Pride provides a focus for campaigning against discrimination amongst those who celebrate their mad identities through arts, poetry as well as radical political action. The diversity of the user movement means there are differences and sometimes conflicts amongst those who consider themselves to be part of it. Not all those who contribute to groups such as NAG consider themselves to be part of a movement. For some it is about being able to develop skills in a supportive environment through acting as volunteers, and they may not be aware of the existence of other user groups or want to get involved beyond the very local level.

The different strategies adopted have consequences for the way in which groups seek to achieve change. Adopting individual and collective advocacy as the major strategy for change meant that NAG has needed to develop and maintain good relationships with service providers, ensuring that they retained credibility and were not seen as overly confrontational, at the same time as being able to challenge policies and practices that were not in users' interests as they saw it. As 'user involvement' has come to be accepted as official policy within the NHS there have been more opportunities for users to work within the system. For example NIMHE in the West Midlands has taken a positive approach to encouraging networks amongst services users in the region and in the East Midlands it has created a regional forum with user representatives from each district. The composition of that forum means that there is no specific place for NAG within it. Some activists within the region have criticised this forum, whilst

others have sought to work within it and use what opportunities it offers to promote user views.

This perhaps illustrates the way in which 'officially' controlled and sponsored initiatives determine the rules by which users have to play. Some feel that one consequence of this is that action by service users has become co-opted by providers and that this has muted its radical edge. Peter Campbell suggested that many groups currently take a 'softly, softly' approach and that there is a need to be more outspoken in public about the state of services - both locally and nationally. At the same time he highlighted how far we have come in 20 years from a time when there was no voice for service users, no credibility for people diagnosed with mental illness, no advocacy, no user led services and no crisis houses. He summed up how he saw the state of the mental health user movement nationally in 2006:

#### *STRENGTHS*

- ❖ Energy
- ❖ Variety of action
- ❖ Courage
- ❖ Excellent ideas and understandings
- ❖ Persistence
- ❖ Humour

#### *WEAKNESSES*

- ❖ Not enough funding.
- ❖ Not radical enough/ too little campaigning.
- ❖ Not enough action by/involvement of minority groups.
- ❖ Not very good at working together group with group.
- ❖ Too willing to be influenced by voluntary organisations (recolonisation is now following decolonisation).
- ❖ Negligible national presence (but beware service user networks being swallowed up by NIMHE).

- ❖ Still too focused on the service system. Currently unable to find way of influencing services and society at same time. Are we in position to ensure messages going out about us to society are ones we really support?
- ❖ Now listened to but still need credibility transfusions.

This list of strengths and weaknesses in many ways reflects the situation of NAG in 2006. The challenge is to turn the crisis created by losing the advocacy contract into an opportunity to renew the commitment to campaigning based on the distinctiveness of a user led organisation and the perspective and experience that this can offer.

## 4. NAG and Mental Health Services

As we have seen the nature of NAG's relationship to the mental health system has been crucial to its development. The significance of the change in relationships between service users and those who plan, manage and deliver services is fundamental to an understanding of the part played by NAG and other service user organisations. In the course of interviews conducted with mental health service purchasers and providers in Nottingham in the early 1990s one acknowledged the extent of the change that had come about in the relationships between users and providers by that time:

...whereas a decade ago the idea that you might pay somebody to criticise you was like an alien concept. It is now almost like, again, come into the culture as any healthy organisation that has got nothing to hide except that it needs, that its users need some sort of advocacy, it has got to have a complaints procedure, and that you actually get brownie points now for buying advocacy as part of the package.

All of those interviewed at this time accepted that NAG was a legitimate and important part of the local mental health system. One told the story of a very public challenge that had had a significant impact on the way service users were viewed. He described a consultative meeting to discuss plans for the re-organisation of services following the closure of the local hospital. This had followed normal practice of such meetings by having a 'top table' of officials on the platform and users and others in the audience. The health authority representative had seen this as an information giving event - this is what we are going to do and what do you think about it? The NAG members there had gone to the meeting thinking it was a genuine consultation about what the HA *should* be doing. When they realised that this was not the case a number of them walked out. Also at this meeting was a woman who was a member of the Community Health Council. When

the NAG group walked out she stood up from the back of the audience and effectively turned the meeting round so that officials were being ignored and users went on to discuss the issues themselves 'more competently than even these skilled professionals could.' She went on to become a long term supporter of NAG.

Acceptance of the legitimacy of NAG as a player within the mental health system was not unconditional. Some spoke of NAG as a pressure group and distinguished what NAG representatives had to say from what *users* thought. One suggested NAG insufficiently represented the experiences of black service users - a point that the group itself acknowledged. Others said it was also important to listen to what carers had to say because 'in providing a service it isn't just for our patients, it is also for the families, and their needs are sometimes different.' There was a view that NAG was a valuable source of access to other networks which could enable service providers to access a wide range of user views. The possibility that NAG's independence would be compromised as a result of funding from service providers was also identified by one person.

Purchasers and providers also had views about what they saw as appropriate roles for NAG. There were four main aspects to this.

Firstly, they thought user groups should challenge professionals. One suggested that 'nobody can pull professional rank or anything of that sort any more.' Others thought that even well meaning and experienced professionals should be prepared to acknowledge that they might get things wrong, and one psychiatrist thought that user groups could be a conduit for complaints that would not come directly to him.

This role of challenging authority was also considered to be important in relation to managers. One said:

What strikes me is how - because I remember it - about how arrogant we were 20 years ago into thinking that, the whole power thing, that we knew what people wanted, and they'd have to obey the rules of where they were going to live in our institutions and all that. It is incredible now to look back to see how different the world was and how County Hall was in charge.

The value of NAG in communicating the message to individual users that dissent was OK was also recognised. And it was also suggested that service providers could benefit from early warnings about the maltreatment which gave rise to scandals and hospital inquiries in the 1960s and 1970s. On a more positive note encouraging feedback from service users was seen as having the potential to improve service quality.

The third role for NAG and other user groups that was identified was an information and education function. This encompassed dispelling myths that 'people who really only have got problems of everyday living yet are labelled as mad or mentally ill and incarcerated in psychiatric hospitals', and more specific involvement in training - in particular Approved Social Worker training.

Finally, NAG was seen to have a direct role in taking part in decision making and other activities: for example in operationalising Patient's Charter standards, selecting staff and in preparing a research proposal.

So how did managers and mental health professionals view NAG during the early 1990s? Inevitably views were mixed, but there were more positive perceptions of NAG and the way it operated than there were negative ones. Although some managers thought it was a reasonably chaotic organisation, with internal conflicts and a primarily reactive stance, there was also a view that group members were very knowledgeable, prepared to work hard and to investigate issues thoroughly, to communicate effectively and genuinely able to reflect user opinion. One particularly positive comment reflected

the significance of the knowledge that NAG members had of mental health services:

I've been escorted to and shown round projects by users and felt lost, inadequate and supported by the users because they have a great deal more expertise and knowledge of the place we were visiting. And it was a very salutary experience in that which just continued to remind me that you can't say that this group of people [managers] have got more knowledge, expertise just because they're on the pay roll and others don't because they happen to be using the service.

Whilst NAG was recognised as having a legitimate and expert role to play there was also a view that it was one amongst many stakeholders taking 'their chance in the game like every body else does.' But there was also a wish to explore how NAG's role in strategic decision making could be strengthened. In a context in which a consumerist ideology was permeating the health service and local government, managers recognised not only that they could not afford *not* to listen to service users, but that 'playing the user card' could be a valuable way of strengthening their position in negotiations with others in the system.

For NAG activists, effective relationships with service providers have been essential to the pursuit of their objectives of improving the lives and experiences of users of mental health services. On the ground their experiences largely reflect the official acceptance of the legitimacy of NAG - there were few accounts of outright rejection of their presence or of the positions they were taking. Resistance, where it happened was more subtle:

They [hospital staff] were quite polite. But I think they regarded the patient councillor as someone who was coming round once a week and not a lot was going to be done.

This comment reflected the day-to-day experience of those working with user councils on hospital wards in the early 1990s. Over 10 years later there was still a view that it was easier to achieve results for individuals than to secure more general changes in the way services were run. There was a sense that if individual patients had a complaint about the way staff treated them, or there were problems with relationships between patients or issues such as accommodation in which to see visitors, that this could be discussed and some solution found. But in relation to issues that affected the patient groups as a whole: like the quality of the food or the physical environment - issues that were described as coming up time and time again, there was frustration about their inability to achieve progress and a sense that it always came down to claims about lack of money. And there was also evidence of defensiveness on the part of some staff on the wards. A letter delivered anonymously to the Patients Council office criticised advocates for believing everything patients told them. This was published in the *Advocateur* and prompted some strong support from some quarters.

Yet there was also a feeling that during this period advocacy became a taken for granted aspect of mental health services in Nottingham. One advocate commented that he was now treated as one of the staff of the hospital and another spoke of the way in which providers were asking for paid advocates rather than volunteers. This appeared to reflect an expectation that they were indeed staff who could and should be available whenever they were needed:

They want somebody who, when their client rings up, can immediately provide an advocate. Or have an advocate within their service so they can contact them themselves.

But we also need to understand broader aspects of NAG's relationship with the mental health system. A key aspect has been the negotiation of agreements for establishing advocacy services. It was John Prices' job to negotiate the agreement that shifted advocacy from an activity that was

more or less accepted by service providers, to a service that was formally agreed and paid for as part of the overall service. The original advocacy service had been established as a 2 year pilot project funded by the Mental Health Foundation. This had been monitored and NAG was able to submit sufficient evidence to demonstrate the need for advocacy and what it could deliver. After considerable discussion NAG was able to secure funding from the Health Authority for a full time post to continue the advocacy service. The agreement that emerged primarily focussed on the process by which advocacy should be delivered, embodying the acceptance that advocates had rights of access to service users and that they should receive support from staff for their work. The principles on which this was based derived from the Dutch patient advocate principles, adapted to the British context. John did not consider that in practice this agreement made a huge difference to advocates' work, but it did provide a benchmark to be referred to if there was a failure to honour the agreement. And it did establish that service users had a right to complain. However, as we have seen, the establishment of advocacy as a service to be bought by the provider organisation eventually led to the decision to buy the service elsewhere. Fears that NAG would become too dependent on statutory sector funding have proved justified.

The 1990s were a time of considerable change within mental health services and this had consequences for the way in which NAG operated. NAG was able to influence the way in which mental health services developed - including the location of new services. As services moved out from Mapperley into a range of community settings, the work of individual and collective advocacy was developed and extended to embrace these changes - and sometimes to challenge the export of institutional practices from the large hospital setting into smaller in-patient or other community based units. NAG had to adapt and organise its services in response to the changing architecture of the mental health system. For example, when case management was introduced NAG negotiated the right of service users to have an advocate at case review meetings.

The period in the late 1990s when there were difficulties within NAG led to some lessening of confidence in those commissioning advocacy services and a suggestion that NAG was being judged unfairly against criteria that were not appropriate to a user led organisation. There was also a suggestion that commissioners were not clear how to judge advocacy and thus could not make a real assessment of the quality of the work being done. For those working as advocates this was a difficult time. John Price suggested that a strong management committee - a 'membrane' which could come between the funders and the actual advocacy activity was important to enable independence to be retained. The problems within the committee at this time felt destabilising.

But in addition to individual and collective advocacy NAG has been involved over the years in a range of activities through which service users have been able to have their say about services as they were developed. When the purchaser/provider split was introduced PUG - the Purchasing for Users Group, was established as a forum in which NAG members could seek to influence the nature of the contracts between the Health Authority and provider Trusts. NAG was also represented in a range of planning forums and members were able to point to specific changes that reflected their input. For example, plans to develop a new unit on what had been the Highbury Hospital site reflected NAG input about the need to separate out people at the time of admission from those who had been in the unit for longer. Through their contacts with services elsewhere NAG members were able to point to innovative developments and encourage providers in Nottingham to have a look and get ideas from them. In these ways the group has acted as a catalyst for change within the service system.

A key change in the nature of the relationship between NAG and service providers came with the advent of 'partnership' as a means of delivering services. The STAR service is one example. This is a core and cluster service offering independent accommodation with access to support services that

was originally provided through a partnership between the health services, the housing service and NAG. NAG's involvement in this offered a challenge to the principles of independent advocacy that the group has championed because they were involved in designing the service with advocacy 'built in' from the start. Kim was appointed to work as the advocate in this service and she described how she tried to ensure that residents understood that she was different from other staff; 'I've got different posters, I'm in the lounge rather than in the office environment.' She spoke positively about the nature of the relationship she had established with other staff working in this unit, emphasising that partnership required listening to others' viewpoints and the difficulty of keeping anything hidden when they all worked together: 'Everything has to be transparent because if it isn't, I can say 'oy, I didn't know about this! What's' going on?' They can't hide anything.'

But NAG also remained in the position of having to negotiate agreements to provide services and was also embroiled in competitive tendering processes. In spite of the increase in advocacy activity there was no additional resource for this service. This created stress and tension for those involved in delivering the service and was also a source of strain for officers of NAG who negotiate contracts. Some left because the strain was too much. Mervyn described coming away from one meeting at which they had only been offered one years' money for a three year job with the expectation that they would fund raise for the remainder. He said 'we went away feeling as rough as we did from any meeting.'

The adoption of competitive tendering alongside an apparent commitment to partnership with service user groups demonstrates the poverty of the concept of 'partnership' being applied here. Colleagues and I called the book we published in 1999 based on research with NAG and a disabled people's organisation: 'Unequal Partners: user groups and community care' in order to reflect the experiences of user led organisations in their relationships with statutory health and social care services. Even in the

early 1990s the concept of partnership was being invoked, mainly by 'officials', to describe the changing relationships between service users and providers. Post the election of the New Labour government in 1997 partnership has become a central theme of public policy. But the widespread adoption of the term does not mean that equality has been achieved, and NAG's recent experience demonstrates the incompatibility of claims to work in partnership with service providers' power to control how advocacy - and user involvement more generally - happens.

One of the experiences recounted by Gladys Bombek illustrates a key characteristic of the current situation. She described the modern matron of the unit where she runs patients' council meetings coming to a meeting and saying that he was there to 'give structure' to the meetings - in line with an item in his job description. Gladys was both dismissive of this and hurt by it. She suggested it demonstrated a lack of understanding about the need to create an informal atmosphere in which users would feel comfortable about talking about things they were not happy with - she said the matron told users to 'pay attention' to what he was saying. But she also regarded it as an attempt to take over something that she had been successfully doing for some years.

NAG's experiences are fairly common to successful social movements. The argument that users should be able to have their say about services has been won - to the extent that it is now official policy within the NHS. One consequence of that is that NHS organizations have 'user involvement' written into their responsibilities and individuals have job descriptions that require them to put this into practice - in ways determined by the service, rather than by user groups. For NAG activists this means that they are experiencing Trust managers 're-inventing the wheel', and seeing user involvement hi-jacked by large charities able and willing to enter into contracts on terms laid down by the Trust. To their chagrin they are hearing Trust managers talk about activities - such as Mental Health Awareness Fortnight- as something that they run, without acknowledging

the origins of this and the extent to which it was NAG that made this happen. They are also seeing the demise of user groups in service settings - such as the Stonebridge centre, that were highly significant in the development of user organization in Nottingham. And they are experiencing the lack of priority given by service providers to the key forum that has provided a focus for a Nottingham wide and Nottingham focused dialogue between service users and providers - the City Wide Council.

As Simon reflected on changing relationships between NAG and health service organizations he suggested this was largely down to who was in power at the time and distinguished between those who it was possible simply to ring up and have a chat with to discuss problems, or who would pop in to talk with them, and those who were guarded by intermediaries and hard to get appointments with. But the move to a county wide Trust has certainly made a difference - perhaps inevitably for relationships with a user group that covers only part of its territory. NAG continues the approach it has pursued throughout its existence of seeking to work with service providers and adapt to changes within the service system, but is finding it hard to develop the informal relationships that have eased that process in the past and unless it were to expand significantly it is not in a position to respond to the move to a county wide service.

In 2006 I spoke with three managers who had varying experiences of NAG over the years in order to understand how they saw the group and its significance in the context of mental health services. The differences in their perspectives on this reflect both the multiple roles NAG has played as well as different views about the significance and potential of initiatives that are distinctive in being led by service users. Their observations can be seen to summarise many of the issues I have identified in considering NAG's relationships with mental health services. It may be significant that the one person who failed to respond to my request for an interview was a current manager with responsibility for user involvement issues.

Mike Harris was acting Chief Executive of the Nottinghamshire Health Care Trust when I spoke to him. But he had been a consultant psychiatrist and Chair of Nottingham MIND when NAG was first set up. He had been involved in the establishment of an advocacy service by MIND which he described as having been set up by professionals but with service users involved in the management group. His view was that from the perspective of professional mental health workers advocacy was necessary because many of those using mental health services were not sufficiently articulate or confident to advocate on their own behalf and needed other people to help them have their say. This might make the work of professionals more difficult - they had to explain and justify what they were doing and this added to the workload, but it was right that they should have to do so.

Mike continued to argue for the importance of advocacy after this was taken over by NAG, but he was less convinced by some of NAG's involvement in other activities. For example, he thought that NAG had let itself be 'manipulated' by service managers to support projects they wanted to pursue. The example he gave was the development of drop in crisis houses run by users. He argued that there is evidence that such services do not work, but an alliance between users and lay managers who also thought they were a good idea led to such a service being established in Nottingham. His view was that NAG was a 'one purpose' organization - an organization that ran advocacy services, and that it was a mistake for the group to have got involved in broader issues around service planning and development and in training. This was not a view shared by other service managers.

Mike felt that MIND in Nottingham had collapsed when professionals were 'pushed out' and service users took over. He remains unconvinced about the value of fully user led organizations, suggesting that the fragility of their mental states means that they are not always well run. Although he is committed to advocacy he does not think that such services have to be provided by users. He gave the example of advocacy services in high secure

services that are run by professionals and perceived by patients as high quality.

In contrast with Mike Harris' perspective, Lynne Winstanley saw NAG as a group that had made a significant input in terms of service planning and development and she had little direct knowledge of their advocacy work. Lynne worked for Nottingham Health Authority as a quality manager when she first had contact with NAG in 1995. This job involved her in seeking to understand the perspective of different groups of service users on issues of service quality. When she was promoted to commissioning manager for the HA she described herself as being in day to day contact with user groups, including NAG, in order to develop her understanding of both users' and carers' experiences.

Lynne emphasized the importance to commissioners of ensuring contact with a wide range of groups in order to reflect the range of experiences and views of those using services in Nottingham. Her view of NAG (reflected in concerns expressed by NAG members) was that it was not representative of the ethnic diversity of service users and that minority ethnic groups in the city lacked a champion giving voice to service user concerns. She suggested that real development in ensuring such a voice had only taken place since 2000. She also expressed concern that NAG tended to reflect the 'traditional' mental health viewpoint. In the wake of the National Service Framework service providers were seeking to respond to the needs of people with complex mental health problems, including those with drug and alcohol problems alongside diagnosed mental illness such as schizophrenia and bipolar disorders. Her view was that those active within NAG were primarily people who had problems relating to depression and that there was a considerable challenge to engage those for whom assertive outreach services were designed. This challenge was being taken up by mental health workers rather than by NAG.

But she recognized the significant contribution NAG had made to the commissioning process. NAG was represented on the Local Implementation Team for the National Service Framework, and on Health Authority commissioning groups. Lynne and her colleagues also used to meet with NAG at the City Wide Council and in the context of the Purchasing for Users Group run by NAG. In addition NAG took part alongside other users, carers and providers in annual stakeholder events. What Lynne described as a 'complex and rich' way of talking with service users and with carers had contributed to the process of determining local priorities for service development. The example she chose to illustrate this was also that of the crisis line and safe house. She identified this as something that users and carers had said they needed and that users had been closely involved in designing. Her perspective was that this service, run by the National Schizophrenia Fellowship, had been operating successfully for 6 years.

Her view of the process of engaging users in these various forums was also very positive. She described these as inclusive processes in which all stakeholders were working together in order to improve mental health services. Users were able to identify key issues for action and commissioners would report back on these. They had received national praise for the way in which users and carers had been involved in the NSF implementation agenda. From her perspective the major factor getting in the way of following through on this was the battles that needed to be fought with health service colleagues to ensure mental health services had sufficient priority in competition with acute services. She thought NAG members did not always recognize the necessity to place advocacy for mental health services in the context of the arguments being made for other services because they were so passionate about seeking improvements for users of mental health services.

Lynne has had no contact with NAG since 2003 when she became Chief executive of Gedling PCT. However her experience of working with NAG has contributed to her continuing commitment to ensure service users are

involved across the spectrum of health services. She shares many of the views from within NAG that when the Trust merged to become a county wide service this created an organization that was too big and impersonal to sustain good relationships with user groups. Her own experience of caring for a close relative with mental health problems has also reinforced her commitment to the need to include user perspectives in determining what a quality service looks like and how to achieve this. She said that this is an integral aspect of how she works and how she thinks the service as a whole should work. For her 'NAG is where it all came from.' But she also thought the NAG had been slow to 'move with the times' and to recognize the necessity to ensure wide representation of user views and perspectives within the group.

Bill Peacham has had experience of NAG both in its advocacy and service planning roles. Bill was a ward manager in Saxondale when the closure process started. He saw NAG's proposal to establish patients' councils on the ward there as timely in providing an opportunity not only for patients to say what they did and did not like in the current situation, but also to start to talk about future plans. From his perspective as a manager of rehabilitation wards the notion of patient empowerment also fitted with his philosophy of rehabilitation. In his words NAG's input was 'manna from heaven.'

The early patients' council meetings focused primarily on day to day life in the hospital: the quality of the food, whether patients were allowed to use the staff club to go for a drink as they were not allowed to leave the hospital. The small victory of opening up this club to patients for an hour early in the evening was described by Bill as an example of the way in which boundaries started to be broken down as a result of user input. The opportunity for patients to have their say was crucial in the run up to the closure of Saxondale and went on to become established routine in the places patients moved on to - the District General Hospital, the day centres

and the rehabilitation units. Bill described the patients' councils as a place where people could complain safely without 'being clobbered.'

What Bill described as the 'implosion' of MIND provided the opportunity for NAG to start to provide a voice for users as a whole. Bill described three types of response from service providers during the first five years of NAG's development. One group completely pooh poohed the idea that users should have their say, another group were not bothered - they would not get in the way, but did nothing to support or help the fledgling user councils, whilst a third group responded positively to what they saw as a valuable addition to the new services being developed after hospital closures. Managers started to get used to taking seriously what service users were saying and some workers recognized the strength that this offered to them in arguing for service improvements. Because NAG had direct lines of communication to senior managers staff could suggest to them issues that they should pursue and be more confident that this would provoke a response than if the suggestion had come from a member of staff. Bill described himself as an advocate of NAG at this time, making sure that either he or his deputy went to their meetings to give feedback on action taken in response to issues raised by users.

When Saxondale closed Bill also moved into community services and continued to support user councils in those settings. He recognized that it was harder to encourage people to come to meetings when they were living in supported housing and had to travel to the day hospital, but for those living in residential units in the community the meetings continued much as they had done in the hospital. He acknowledged that it continues to be a problem to ensure that those who live in their own homes and are not well connected to services get the information they need and the support of advocates to ensure their rights are protected.

Bill described this period as a lively time with many discussions about what services would look like after hospital closures and active consideration of

the different models of service that might be developed. NAG was an important part of these discussions and these were also stimulated by Wouter's visit from Holland. Bill continued to work in Trust services and to support NAG's development. He said the last thing he did before leaving the Trust was to secure funding for a NAG worker to work on the acute wards. In 2002 he moved out of Nottingham and started to work for NIMHE where he continues to work with NAG and other user and carer groups in the East Midlands. He is therefore able to compare the situation regarding user activity in Nottingham with that in other areas. His view as a result of this is that user groups are very dependant on the existence of individuals with the energy and vision to continue to push and challenge. If such people exist then advocacy is viewed as exciting and forward looking. In their absence there is a tendency for things to collapse - until someone else picks up the reins. In Nottingham the consistency of Colin's input over many years had meant that NAG was able to sustain its activity and profile. And Colin's capacity to hand hold others to enable them to develop has meant he has been able to pass on the mantle - as the stories told by NAG activists testifies. Another benefit of this consistent involvement has been that there was someone who remembered the promises made to service users and could embarrass providers if they try to renege on these.

Bill said he still hears about what is going on in Nottingham but he is no longer directly involved in this. He suggested that the Trust were looking for another group to take over the advocacy contract when tenders were invited and speculated that NAG was seen as so powerful that nurturing another group would make it easier to engage in a competitive tendering process. His view is that the group that has taken over the advocacy contract is doing things very differently from NAG. Bill suggested it would be interesting to see what happens when the Trust achieves Foundation status. This will require them to access a wide range of user voices - including those who recover and have no further contact with services, and potential future users. It could be argued that only a limited group of users can be accessed via NAG.

Bill is obviously a long term supporter of NAG and in his speculations about likely futures he emphasized just what a huge contribution NAG has made to user involvement and to the development of mental health services - not only in Nottingham but in the region and beyond. But he recognized the tendency of the health service to 'bring into the fold' things that are positively regarded, when the strengths of such activities might be linked to their being outside the fold. This is another reflection on the debate that has taken place within NAG and in the user movement more generally. One suggestion is that NAG might focus on what he referred to as 'true advocacy' - working with individual service users or a group of users to do a specific piece of work and then move on, rather than trying to sustain an ongoing relationship and to try to represent the user group as a whole. Bill suggested that if NAG were not able to change it would not survive - and if there is no change then maybe NAG has done what it needed to and it is time to move on.

In the final chapter I pick up on key issue raised in these responses to reflect on NAG's future.

## 5. NAG in 2006 - where next?

The world in late 2006 is a very different place from the mid 1980s when service users in Nottingham took the first steps towards establishing what became the Nottingham Advocacy Group. It may have felt incredible to those who first raised their voices to challenge the day to day treatment of patients on long stay and acute wards to think that 20 years later users would be regularly involved in discussions with policy makers and those responsible for service development; that users and survivors of mental health services would be designing and delivering training to mental health professionals and working alongside academic colleagues in carrying out research. The success of NAG and other groups that collectively comprise the mental health service user movement is that not only is such action no longer exceptional, it is also official Department of Health policy. For many of those who have been part of these developments during the last 20 years this involvement has had a transformative effect. They have not only survived, but flourished as a result of being part of a movement that has recognised the value of their strengths and experiences, modelled a way of relating to others that acknowledges vulnerability without assuming this implies lack of competence, and has enabled them to use their own experiences and understandings to help others find a way through what is often a frightening and painful experience.

NAG has played a key role in bringing about this transformation. But in doing so it has also reached a point at which there is a need for a hard look at what its future role should be and how it can continue to offer a distinctive support and voice for people who live with mental health problems. There are a number of issues which this history suggests will be important to consider as NAG moves forward.

The first and enduring issue is the exact nature of NAG's relationships with the mental health system. The interviews with mental health service

managers who have been involved with NAG over the years demonstrated important differences in the way that NAG is viewed from within mental health services. That is not surprising and it would be unrealistic to expect either a common view on the role user organisations may play or common assessments of the success with which they play these roles. NAG cannot expect to successfully be all things to all people within the mental health system. But it is important to reflect on the significance of the official acceptance of user involvement within the NHS and social care services provided by local government and independent service providers and work out strategies appropriate to that changed situation.

One aspect of that obviously concerns sources of funding to support NAG's work. The current situation illustrates the danger of depending on statutory organisations as funders, although the difficulties NAG faces in this respect are common to most voluntary and user organisations. NAG's future security is most likely to be achieved via obtaining funding from a variety of sources - and other issues discussed below also relate to this.

Both NAG activists and mental health workers have acknowledged that NAG has been more successful in engaging some groups of users than others. Black service users have never been involved in NAG and the group has often struggled to engage with younger people. It has worked successfully with people in different service settings, including forensic services and has developed specialist work with people with personality disorders. One strategy would be to develop special expertise in selected areas rather than seek to sustain an across the board advocacy service.

As a researcher I have long argued the importance of collaboration between service users and academic researchers. Whilst the relationship between research and action is far from straightforward, research can lead to new ways of thinking about problems, policies and services and can generate new understandings essential to achieving change. Service users who have taken part in research can develop new confidence and new

skills - and there is evidence of the impact of that in the employment of service users in the Centre for Excellence in Interdisciplinary Mental Health at the University of Birmingham. The SureSearch user researcher network there has become a well established and respected groups undertaking a wide range of research with academic colleagues. This is another route of potential development for NAG. It did attempt something of this with NSURE and it may be worth reviving interest in this.

Throughout its history NAG has prioritised work to represent service users to mental health services and to influence the design of such services in the interests of users. But some aspects of its work have also reflected broader aspects of what it means to live with mental health problems. One strategy would be to raise the profile for this work which could then attract funding from sources outside the mental health system. Alongside moves to enable service users to have a greater say over services and policies have been national and local initiatives focussed on enabling people who live in neighbourhoods experiencing poor health generally, poverty, poor housing and other forms of disadvantage to become involved in broadly based regeneration initiatives. New Deal for Communities, the Neighbourhood Renewal Fund and Sure Start Local Programmes have all aimed to involve people living in poor communities in action to improve their lives and those of their children. Community safety and public health initiatives also address issues that directly affect the lives of people who live with mental health problems. Locally based action can be difficult for many mental health service users because of the stigma attached to mental illness. But NAG could consider building on the work it has done through the mental health awareness weeks to ensure that locally based regeneration and community development programmes include and address such issues head on.

But fundamental to any future strategy is the absolute necessity to maintain and develop grass roots contacts. NAG's authority, purpose and strength comes from being a space in which people who use mental health services

can develop their own identities and draw on their own experiential knowledge to challenge both professional and lay constructions of what it means to live with mental illness, and to build more helpful and respectful responses within the mental health system and beyond. The testimonies of those whose stories I have told here demonstrate the valuable personal impact that comes from being a part of this process. The way in which that is achieved is through being encouraged, supported and sometimes trained by others who have trod the path before them. This is what makes NAG and other user groups different from voluntary organisations or professional advocacy service providers.

When NAG started out mental health services were provided collectively and the access route to service users was clear cut - even if gatekeepers were not always entirely helpful. Twenty years later it is more complicated - the system is both more dispersed and more centralised with a local service provider that has a broader geographical remit than Nottingham city, and which is about to become a Foundation Trust and will thus adopt an approach to 'user involvement' laid down by government. So NAG must be creative in working at the grass roots to maintain its existing contacts and enable those who are finding themselves for the first time needing to make contact with mental health services. One implication of this is that the group needs to address an area that it has previously had little success in - that is attracting and working with young people. But beyond this NAG, like service providers, needs to be thinking about how to reach out to those who remain isolated and disconnected from sources of support.

The Nottingham Advocacy Group is recognised as having played an essential role in the development of the user movement in England as well as having offered a lifeline to many in Nottingham who have worked with or been supported by it. Appealing to that history is not enough to guarantee a future, but it is important as a means of understanding the significance of the work that the group has done and continues to do. 2006 has been a difficult year, but NAG has faced other difficult years during its history and

it has survived. And I imagine few would suggest that there is no further need for the support that it can offer. NAG from 2007 may look rather different, but all those committed to ensuring fair treatment for users of mental health services should hope that the group continues well into its next decade.