A CHANCE TO SPEAK OUT

Consulting Service Users *and* Carers *about* Community Care

Edited by
Alison Wertheimer

KING'S FUND CENTRE

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The King's Fund Centre is a health services development agency which promotes improvements in health and social care. We do this by working with people in health services, in social services, in voluntary agencies, and with the users of their services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences and publications. Our aim is to ensure that good developments in health and social care are widely taken up.

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Appendix, page 39). She has also edited this report, bringing together the writings of different contributors and producing practical guidance which we feel sure will help others in the community care field as they consult carers and users.

- Lydia Yee, Martin Bould, Keith Hawkins, Collette Curran, and Yasmin Gunaratnam who have worked with us in writing this report.

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INTRODUCTION

Introducing his report on community care, Sir Roy Griffiths pointed to the enormous gap which exists between political rhetoric and policies on the one hand, and consumer satisfaction on the other. 'Present arrangement', he went on to say, 'do not encourage systematic attempts to discover how helpful services are perceived to be by the consumers'. In other words, no-one has asked the consumers what they think.

The subsequent White Paper attempted to remedy this by proposing that people should have a 'greater individual say in how they live their lives and the services they need to help them to do so', stressing that services should 'respond flexibly and sensitively to the needs of individuals and their carers'. When drawing up their community care plans, local authorities were urged to 'consult with and take account of the views of of service users and carers'. Although the White Paper did not spell out exactly how this was to be done, it placed consultation with carers and users firmly on the agenda.

The government's decision to postpone the full implementation of the changes proposed in the White Paper has been greeted with dismay by many, concerned that this might signal a weakening commitment to the changes on the part of government. However, local authorities could use the time in a positive fashion by developing the necessary structures to ensure that in 1993, new services are both needs-led and consumer-oriented.

The history of consultation with service users and carers has not been a particularly happy one. Attempts have often been half-hearted, token in approach, and have failed to take on board the need to embark on consultation well before plans begin to take shape. Plans may not always be written on tablets of stone but they do have a habit of resisting amendment once they have been drafted.

This report documents an important experiment in consultation undertaken jointly by the Carers Unit and the Community Living Development Team at the King's Fund Centre who felt that existing methods of consultation with users and carers were less than satisfactory. The search conference, which is the subject of this report, presents an alternative model for consideration by local and health authorities, and by users and carers themselves.

It was undertaken as a demonstration project and as such it does not claim to be perfect, or indeed the only, model. As the reflections from three of the participants make clear, with hindsight, certain things might have been done differently, but despite this, we feel it is a model we can strongly recommend to all those charged with consulting service users and carers.

Genuine consultation, undertaken with a real commitment to taking on board what users and carers are saying, is costly. When services have for decades been provided on the basis of 'we know what's best for you', it is not easy to be told that maybe we didn't always have the best interests of users and carers at heart. Professionals can find it hard to acknowledge that it is people with disabilities themselves who know most about what it is like to live with a disability.

As those who organised the search conference make abundantly clear, it costs time and money to organise an event of this kind. Perhaps it is time that more resources were allocated to consultation, so that it was seen as an accepted part of the cost of setting up and running services. Consultation should not be seen as a luxury – it is a necessity.

We hope that this report will be of use to local authorities, health authorities, and all those who provide services to people with long-term disabilities and their carers. We have included a certain amount of practical information; we feel that others may learn from the way we went about planning the search conference – and can benefit from our mistakes!

Planning and organising the search conference entailed a good deal of hard work, and it challenged some of our assumptions about users and carers – nevertheless, we found it a worthwhile exercise and one we would warmly recommend to others.

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BACKGROUND TO THE SEARCH CONFERENCE

The idea of holding a search conference arose from discussions between the Carers Unit and the Community Living Development Team at the King's Fund Centre. The teams shared a key interest in the development of community services for people with long term disabilities and their carers, and both had been involved in discussions on the Griffiths Report on community care and the subsequent White Paper, *Caring for People* (1989), which set out the government's proposals for the future of community care. By 1990, health and local authorities were already busy deciding how they would implement these new policies, but we were increasingly concerned about the way they were going about this.

The White Paper placed considerable emphasis on consultation with users and carers (see above), and one of our major concerns was that local authorities were forging ahead without taking on board the views of consumers. From our numerous contacts around the country, we knew that very little real consultation was taking place – partly because many authorities were uncertain how to go about it.

One of the main stumbling blocks was the random and haphazard way in which local authorities were approaching the whole business of consultation. With no single tried and tested model available to them, individual authorities tended to fall back on conventional – and not particularly effective – methods: sending out plans with a request for written feedback or holding meetings at which the authority told those present what they were proposing. The main drawback of both these approaches was – and is – that the consultation starts too late in the day, and often when proposals, deadlines, and budgets have already been decided in principle.

It is little wonder, then, that when asked for their views about new community care developments, many users and carers feared that what they had to say would not be taken seriously. They sensed that consultation came too late in the day when key decisions had already been made, the implication being that their views were not to be taken too seriously.

In our view, though, it is essential that the people who use services are fully involved when plans are being drawn up. Our own experience has taught us that users and carers are the real experts when it comes to thinking about community care. They are the people with round-the-clock experience of living with disability or of caring for someone with a disability.

Demonstrating a new form of consultation

The Carers Unit and the Community Living Development Team realised that to achieve consultation which was more than a token nod in the direction of users and carers, a different approach was needed. It seemed to us that one useful contribution we could make would be to organise an event which would give service users a voice to speak out on community care. Rather than asking them to comment on existing policies and plans, we wanted to provide the opportunity for users and carers to give a fresh and direct account of what *they* wanted from services. With this in mind, we drew up the following broad aims:

- to ask users and carers about their lives and about their current experiences of using community care services;
- to encourage service users and carers to exchange information on how the White Paper proposals will affect their lives;
- to enable users and carers to put forward their views about how they would like to see community care developing in the future;
- to gain a clearer understanding for ourselves of the concerns to policy-makers and professionals;
- to demonstrate a method of consultation which the statutory authorities could themselves use;
- to demonstrate that consultation can involve a range of people with different disabilities and from differing racial and cultural backgrounds.

In starting to think about this event, we were aware that anything we could organise would have some severe limitations. For a start, we would only be able to work with people over a short period of time. For local authorities and other community care agencies, it is essential that they set up a continuing dialogue with users and carers. A one-off event along the lines of a search conference could be a useful starting point, but it would need to be followed up by regular contact and consultation.

A further limitation was imposed by the fact that the King's Fund Centre does not itself plan and run services, so we were not in a position to make changes to the services which participants were using. Neither could we promise that what they had to say would directly change those services.

But despite these limitations, we decided that a search conference with users and carers would still be a worthwhile exercise, not least because it could demonstrate a fresh approach to consultation to those organisations which are in the business of planning and running services.

The search conference model

The 'search conference' method, pioneered at the Tavistock Institute of Human Relations in the 1960s, aims to encourage mutual understanding and co-ordinated action among different groups who share a common concern about a particular issue or set of issues, but who approach it from different perspectives. The 'search process' enables people to work in a way which recognises and takes account of their differences and we felt it could, therefore, be a means of bringing together carers and users – whose needs and wishes do sometimes differ.

The aim of a search conference is for participants to reach a mutual understanding of each others' situations, something which rarely occurs in other conferences and meetings. Seasoned conference attenders will be used to speakers attempting to win over the audience to their point of view. Meetings are frequently set up with the purpose of reaching a majority decision – with the implication that those in the minority are 'wrong' or have 'lost'. In the search process there are no winners and losers, and no right or wrong answers; participants are there to reach an understanding of one anothers' points of view.

This approach also assumes that everyone's point of view is equally valid and that everyone has a right to express those views. Unlike conferences where those on the platform are seen as the 'experts' whose views must predominate, the search method assumes that everyone present is an expert and the resources available to participants are the contributions of all. This was particularly relevant, because it reinforced our own view – that when it comes to community care the experts are people with disabilities and their carers.

The search process attaches considerable importance to valuing and accepting the contributions that each person brings to the discussions, and that was important too. With the traditional conference structure, most of the available time is usually allocated to a small number of 'speakers' with a brief period for 'questions from the floor'. By way of contrast, most of the search conference is spent working in small groups which means that everyone has the chance to contribute to the discussions.

Finally, the search conference participants attend as individuals. They may have a particular affiliation (e.g. chairperson of a carers' group, or member of a local disability group), but they are not attending to put forward an organisation's point of view.

How a search conference works

The model has a very specific structure and there are five main stages to the conference (see page 8). In our case, the common issue was the White Paper and the future of community care and the five main questions we discussed were as follows:

1. What are the current major influences on the lives of disabled people and carers?
2. If current trends and patterns continue, what will the future look like for disabled people and carers?

3. In the light of experience, what would an ideal future look like?
4. What opportunities are there to help us move towards a desirable future and what constraints must be overcome?
5. What can we do to move forward?

In order for participants to work in the ways described above, the search model has a number of good ground rules which everyone is asked to adhere to. As participants, you are expected to:

- be committed to exploring the issues which other participants see as important, even if they are not seen as important by you;
- speak as an individual, rather than as a spokesperson for any particular group, agency or other affiliation;
- recognise and respect other people's opinions and refrain from trying to win them over to your point of view;
- attend all sessions in order not to disrupt the process;
- be willing to participate fully and actively in the process and take responsibility for your own input;
- be committed to carrying forward what has been learned at the conference, and to working out at least one thing you will do as a result of being at the conference.

The planning group for this particular search group added the following ground rules:

- share with other group members the responsibility for making sure that everyone has the opportunity to contribute and be heard, by:

  - recognising and respecting differences of race, culture and class, sexuality and age, etc;
  - and by recognising and respecting differences in knowledge, skills and experience;
- ➤ we want group members to feel free to say if they do not understand something and to help each other by explaining and sharing knowledge and ideas.

Having decided that we would like to use this search conference format, the next stage was to start planning the event.

Summary

- ➤ The search conference brings together people with differing views on a common issue or set of issues;
- ➤ the aim is not to reach a majority view but to reach a mutual understanding of each other's views;
- ➤ all the participants are experts and everyone's views are equally valid – there are no 'right' or 'wrong' views;
- ➤ the resources available to the group are the contributions of all those present;
- ➤ participants are expected to work within an agreed set of ground rules.

THE SEARCH PROCESS

Stage One
Scanning The Environment

Stage Two
The Probable Future

Stage Three
Defining The Desirable Future

SEARCH STAGE

Stage Four
Analysis of Opportunities and
Constraints and Ways Forward

Stage Five
Identification of Issues,
Tasks and Ways Forward

ACTION STAGE

Post Conference Activities

PLANNING THE SEARCH CONFERENCE

Discussions between the Carers Unit and the Community Living Development Team led to two key decisions being made. We decided that our own thinking on the community care White Paper needed to be based on clearer ideas of what carers and users thought about the proposals it made. We had also concluded that holding a search conference would be one way of going about this task and that an exercise of this kind could also demonstrate a different form of consultation to service-providing agencies. A number of further decisions now had to be taken, and we embarked on the planning process.

Planning group

We decided to set up a planning group, although the usual questions and misgivings cropped up. Who should be on it? Who would give up the time to come to meetings? Would it not simply lengthen the process? In order to provide a tight structure, we organised just two meetings a week apart, but in fact, people were so committed they offered to come a third time! A lot of ground was cleared at this stage. We agreed to the main principles, allocated various tasks between organisations, and generally began to develop a shared understanding between users and carers.

Deciding who should be asked to join the planning group was less straightforward. We invited people with disabilities who had experience of helping organisations plan similar events: People First, Survivors Speak Out, the London Boroughs Disability Resource Team were all involved. We invited an Asian carer who worked in social services, a worker from the Carers National Association; a carer who used her local Crossroads Scheme was also invited and her contributions were invaluable, being direct and all the more telling because she did not bring the habits and constraints of a 'committee person'. We also found it useful to have people who had either already attended a search conference or who had experience of talking in joint forums with users and carers.

Involving users and carers at the planning stage is essential, even if what they have to say challenges or contradicts the assumptions of paid workers, and the planning group has to take these differences on board.

Key issues for planning

Once the broad principles had been agreed (that it should be an event for carers and users and that we should use the search conference format), key decisions had to be made about how we would best meet our aims, within the amount of time and funding at our disposal (neither being unlimited).

Time needed

We decided on a two-day event, with a week between the first and second days. We briefly considered a three-day residential event, but rejected it both on the grounds of cost and because we felt that participants would be unable to spare that length of time away from other commitments. Carers, for example, would find it difficult to arrange substitute care. Even a residential event of two consecutive days seemed potentially too disruptive. In the event, our chosen strategy worked well, with no falling off of commitment.

Cost

When we began to cost out the event this really tested our motivation for going ahead. With two days room hire and meals, plus a small group of facilitators, and paying transport costs and sitters the expenses began to mount up. But despite this we never considered charging users and carers. We would recommend this approach/policy to others. We felt that it would not be reasonable to charge participants who were there to offer and to share their expertise and knowledge. It should be borne in mind, too, that many people with disabilities and carers are on low incomes or rely on benefits.

Allocating human resources to pre-conference organisation

The support which the participants needed, e.g. interpreting services and the number of different strands which had to be woven together, involved a great deal of detailed practical planning and organisation, and one King's Fund worker took specific responsibility for this. This was a positive strategy. However, you do need to remember to allocate time after the conference for follow-up work. We rather skimped on this, with the result that some practical follow-up tasks were delayed.

How many participants?

The lower and upper limits were 30-50 participants. The maximum was governed by space available for small groups, which could not have more than 12, nor, we decided less than seven. We had five groups, each with two facilitators. It is an advantage to use pairs of facilitators, and we would recommend it. With two people, one can record while the other facilitates or one can observe while the other is interacting with group members; this can also provide mutual support. But in some situations, and with sufficient support from non-facilitators it may be possible to use one.

Involving users and carers

One of the key messages from the planning group was that the people doing the facilitating and media reporting should themselves be users or carers. This can be difficult for any group of professionals to take on board and we were no exception. Professionals are used to judging people on the basis of their skills and experience. You may not know users and carers who possess such skills; or such individuals may not have had a proper chance to prove them. Nevertheless, we tried to adopt this strategy and half the facilitators were users or carers, although there were no people with disabilities or carers reporting the event. On the other hand, all the facilitators we employed, and the writer we employed to produce the article appended to this report and to edit the report itself, were very familiar with community care issues and had worked extensively with users and carers. (Only one facilitator worked for the King's Fund Centre, and he was a reserve.)

Reaching out to Black communities

Involving Black workers at the King's Fund Centre and having a Black carer on the planning group meant we could make contact with Black users and carers through the projects they worked with and the individuals they knew. We were able to find enough Black users and carers to take part in the conference. Being able to deliver on this issue, we felt, was an essential part of our attempt to break new ground in consultation.

The participants

Some key decisions had to be taken about the kind of people we wanted to attend. We agreed that we did not want to go for 'seasoned conference attenders'; they would have other chances to put forward their views. Although we recognised that some participants might have affiliations to voluntary agencies or local projects, it was their personal views and experience we wanted.

The other principle we adopted in terms of participants was balance. We wanted a range of different experiences and roughly equal numbers of users and carers. We did not, however, feel it was appropriate to set a fixed quota for each disability or racial grouping. The overall numbers were too small. We determined to rely on trust and on what was practicable.

We felt it was inappropriate to have people who were not either users or carers even though we could see that workers in statutory and voluntary agencies might benefit from hearing participants' views, and might find it a helpful learning experience. We judged that the pressure of 'outsiders' might disrupt the small groups too much.

Outcomes

The final item which the planning group had to agree on was our expected outcomes. We agreed that at the very least the event should be of some benefit to King's Fund Centre teams, should offer a positive experience for individuals which they could take back to their own network, and should result in some key lessons to disseminate.

SUMMARY

What we needed:

- two days to enable us to complete the full search conference
- an accessible building with several small group discussion rooms
- at least £5,000 earmarked
- one day a week for ten weeks of the organiser's time
- 30-50 participants
- policies on:
  - involving users and carers
  - reaching out to Black communities
  - desired range and balance of participants
  - acceptable outcomes.

ADVICE ON PRACTICAL ORGANISATION

Adapting the process

One of the most important things for us to do was to adapt the search conference method and make its language and style accessible to non-professionals. All the participants received advance information on the search method, in what we hoped was jargon free language, and were invited to ask for further details if needed.

The workshop facilitators were invited to two pre-conference briefing meetings to familiarise themselves with the "search" method. We also stressed that the aim was to draw on the experiences and knowledge of both users and carers present, it was not to be a problem-solving exercise, and there were no right or wrong ideas.

The main criticism which participants made about the search method was that the timetable was too rigid, with too little time except during the breaks for people to get to know each other. Not being regular conference attenders, many participants were unused to conventional meetings where keeping to time plays an important role. They would have liked more flexible timetabling, with less emphasis on "reaching the end", and "getting through the agenda". People wanted more time to begin to feel comfortable in the group which would have enabled them to express their experiences and ideas more fully.

Identifying participants

We realised it would be difficult to identify people who were not conference goers, so we decided to use our contacts (mainly professionals) in local areas to invite users and carers to the conference on our behalf. This worked much better than a "cold" approach from the King's Fund Centre, it prepared participants for the conference informally because they could discuss it with people they already knew and these local contacts were in a better position to discuss any misgivings or worries that people might have about attending.

Arranging the support

Getting this right was the most important aspect of the two days. Both users and carers were encouraged to bring friends, partners or family members if they felt unsure about attending alone or needed assistance of any kind and many users did bring someone with them – usually a partner or a personal care assistant. Partners attending the conference could choose whether to be in the same workshop or not. Many carers and users who attended as partners did, in fact, prefer to attend separate workshops because they felt less inhibited about expressing their feelings.

Apart from the meeting rooms, there was also a room for participants who wanted to relax, rest, or take medication. In addition, a member of the planning group was always available at a central point to offer assitance to participants and facilitators.

Free creche facilities were available on both days. We also offered to pay any expenses incurred by participants, and these were mainly for a sitting service for dependants at home, and for travel costs.

Interpreters were available on both days, although it had been difficult to ensure that those who understood or spoke little English could participate fully in the two days. We had been advised that having simultaneous translation equipment would be excluding by its very nature, so we finally decided to have interpreters present in the workshops with participants. As this would slow down the proceedings, both participants and facilitators were asked to be patient. The interpreters were also briefed on the search method and reminded that they must express the views of the non-English speaking participants and not their own!

The media were invited to attend at a specified time. Participants were aware of this and agreed to it. Representatives of the media, for their part, were asked to avoid sensational or devaluing reporting.

On the whole, we found that the search conference format worked well and the support facilities enabled users and carers to participate fully. However, the evaluation forms completed by participants and facilitators at the end of the two days reminded us that we had overlooked a couple of important matters:

- the abundance of chairs in the meeting rooms and the dining area showed a lack of foresight in accommodating space for wheelchair users; and
- the lack of any 'counselling' provision for participants and facilitatrs, either during or after the conference, meant that people unused to sharing sometimes painful experiences with strangers, did not receive the kind of help and support which would have made this easier for them.

A USER'S REFLECTIONS

This report was compiled by a worker conducting an interview with the user whose comments are set out below:

What were your reasons for attending the conference?

I thought I'd go because it was interesting to hear what people wanted to say.

I felt that I was going there to take part, to go and take in what was going on, and listen to what other people were saying.

How did you feel people got on with listening to one another?

We all had a chance to speak and everybody got a chance to talk. I felt that it was quite important that when one person speaks then the other one stops, then you could hear what the other person was saying.

There were people talking different languages and I thought it was a shame that when they were speaking you couldn't get to realise what they were saying.

I was happy with the way people came up with their own suggestions about what they wanted. I spoke and said that everybody had a right to say what they wanted to say. I felt fine because I thought I knew that people were only speaking for their own point of view.

I think the purpose of having that conference was to go there and to actually listen and to take in what other people were talking about. I think that everybody had a chance to say what they wanted to say.

What were people talking about?

The most important things we talked about were helping people to be independent, going out and about, and about money. People were not happy about the amount of money they had to live on.

They were saying about how they didn't get enough money to live on, to pay the rent. There were a lot of people angry and saying why weren't they getting enough money.

One or two people said they didn't like the place they were living in, and they wanted to get out and live somewhere else because they felt where they were living was too small.

People were saying how they weren't happy about how things in life were organised, how much social security was paying them, and that they wanted to go out and find a job. They were saying how they wanted to get their own home, away from their mum and dad and that they wanted to live independently on their own.

What about the people who need help?

People in wheelchairs had to be taken out and they were speaking about going out in the street.

There was quite a bit of talk about getting on with people and with helping people if they've got difficulties with talking and with their speech, or if they have learning difficulties.

I think with my life I'm lucky that I can talk and do things but you do see people in wheelchairs who have to be taken out and taken to the toilet with some support from other people. I feel myself that people like that should have more help.

I find that it's not very nice to laugh (at people with disabilities) and take the rise because it's not funny. Some people there couldn't ask if they wanted a drink or a biscuit, they had to be asked first. It was really important to help people who couldn't talk.

What are your final thoughts about the day?

The food was really nice there. I enjoyed it a lot.

I think people may have learned some things (from the conference) and the only way they can find it is by going to ask other people for help.

I hoped that everything was going to come out really well with our talking and so on. The others thoroughly enjoyed themselves too and they said to me that it was a good conference.

A CARER'S THOUGHTS

After the initial excitement, and trepidation at what to say on being asked to write about my thoughts on the search conference held at the King's Fund Centre some months ago, it occurred to me there could be some correlation between what I could recall and how "effective" the event had actually been.

I am writing this solely from memory, so what do I remember about the two days? The first thing that comes to mind is the time that my wife and I had to get up. As a "carer", – I hate that word – it takes me about one-and-a-half hours to do what is necessary to ensure that Pamela is up and mobile and independent in her powered wheelchair. This is one-and-a-half hours on top of anything else I, or we, want or need to do each day.

The venue in Camden was very pleasant, roomy, and warm, and the food was also much better than I expected. The first get-together, which was to explain what was to happen, was on the whole quite explicit, but some of those present who required an interpreter were left somewhat bewildered as the translators could not keep up. I wonder if at future events a pre-prepared factsheet in various languages could be made available? Some people with learning difficulties were also finding it hard to keep up with what was being said.

My group consisted of a person with HIV, a person with learning difficulties, an older female carer and, I think, three women carers who needed a translator, and me – a youngish male!

It took many hours for some people to drop their defences and "open up". Apart from myself, the other male, and the female translator, none of the group had been to any similar events, and they were very reticent to take the lead on any subject; they were also less informed on such relevant issues as the disability movement; welfare benefits; and social services provision.

The "search process" not only highlighted the many differences between us, but showed the near impossibility of reconciling opposite and opposing views. Some blatantly political viewpoints were expressed ranging from those of the extreme left to those of the far right; there were widely divergent opinions about how these should be provided, ranging from the statements that the family should act as carers to my own that there should be funding for independent living by means of self-operated care schemes for those who wish to take advantage of it. However, I do not wish to write pages on all the views expressed, as I am sure these are well recorded and documented. Flip charts were used to record what was said on both small group and plenary sessions.

I would like to look at the search method and the problems, as I see them, in using it. I have very strong, long-standing views, which are often debated and attacked, and, I would like to think, they are well thought-out and constructed. Furthermore, I have experience of speaking at various events. Some of the group unfortunately had great difficulty in understanding what was being said, and, with the best will in the world, either lacked or were unable to express any constructive views of their own. This meant that three of our group – without wishing to, I would like to emphasise – dominated the discussions. To try and counter this I deliberately, on occasion, held back from expressing my views; indeed, I asked other individuals in the group for their views. I am sure the facilitators were aware of this, and tried to include everyone in the discussion, but when we moved on and discussed the Griffiths Report an even larger gulf emerged between the participants.

Again, some of us (well, me!) had read and knew something about the report, but the majority of the group knew very little about it. I would have liked to have been able to discuss some of the issues it raised in greater detail, but that was just not possible. For example, I would like to have talked about the following:

1. Funding: Who would it go to, how would it be administered, and whose interest would be paramount?
2. The recruitment of care attendants: who should vet them for honesty, competence, suitability, and, who should train them for this work?
3. Who would maintain and set the standards required in services?
4. Would the case manager have independence in assessing requirements and not be tied to operating within a specific budget?
5. Would the care in the community services be operating for the benefit of the Social Services department, the staff who administer them, or all the providers brought in who must make a profit from the schemes? For example, would services be sufficiently flexible to meet individual users' needs and preferences?

In the long term, I think those who attended such a conference for the first time gained the most. Firstly, from hearing viewpoints which differed from their own: secondly, being able to express their pent-up feelings, often for the first time: and thirdly, from meeting other people in a similar – or sometimes worse – situation to their own. Hopefully, some people will go on to join self-help groups, or similar bodies, and begin to fight for their rights. It is quite a comfort to know you are not alone and this was one of the positive achievements of the conference.

But having heard all the voices and views expressed at this two-day conference, I am left with the question: does the Government really take note of the report produced at the end of the conference or are the records left to gather dust, and, at some future point, either destroyed or examined by social historians who will then attempt to explain why carers and disabled people were treated as they are today namely, as a burden on a society which tried to ensure that the environment humankind builds is about as hostile as possible to disabled people. This in turn ensures disabled people are segregated and classified as being in need of people to care for them.

I think most people imagine that Care in the Community encompasses a very narrow, tunnel-like viewpoint. It ignores the reasons why so many disabled people are dependent upon benefits, which in turn create the very dependency which ensures a disability industry thrives and in which so many non-disabled people are employed. In whose interest is it to ensure it continues thus? It was a great disappointment to me that this issue, when I raised it within my group, was simply not understood by most of the others present. I feel they are conditioned into dependency by the very society which discriminates and oppresses them, and because of this change will not happen.

At the end of the day, this means that if we get invited to another conference, I will still have to get up one-and-a-half hours before you to "care" for my wife and drive her to London. I guess if there is some correlation between the quality of the conference and how much value one derived from it, your conference provided an outlet for "novices", a chance for them to voice opinions rarely heard.

I think it only fair to say at this point that my comments are based purely on my experience within my own group: others attending may well have had different experiences in their group.

The comments of participants at the final session of the conference would indicate that this was so.

A FACILITATOR'S VIEW

One of the first thoughts that crossed my mind when I was asked to be a facilitator was that the "search conference" process was just another fancy label for what good facilitators should be doing anyway – namely, guiding discussion, enabling full participation, providing an objective summary and, if necessary, recording key points and issues. My subsequent experience as a facilitator using the search conference method showed me not only exactly how the method extends beyond these "traditional" skills but also highlighted the need for organisers to review and customise the method according to the particular situation.

So how does the search conference differ from other forms of consultation? From the facilitator's point of view, there was the immediate issue of accountability. Unlike most situations, in which facilitators are primarily accountable to the overall conference brief and its objectives, search facilitators are also accountable to predetermined search ground rules. This in itself narrows down the dangers of opportunistic and haphazard facilitating. Search facilitators are task-orientated, in that they have to guide participants through the different issues posed at each stage of the conference, but facilitators (and participants) are also accountable for the process by which the participants arrive at an understanding of the issues. The search ground rules are central to both the roles of participants and facilitators. In other words, the process involved – how the search conference model generates – is as important as the content – what participants have to say.

The degree to which participants and facilitators commit themselves to the ground rules is, however, entirely dependent upon the relevance of those rules. In view of the diversity of identities of both facilitators and participants, I welcomed the fact that the conference planning group had reviewed and developed the original search ground rules; as a Black woman, I was particularly wary of their "wishy-washiness" and their emphasis on "the individual", and individual participation which ignored the issue of power relations. The King's Fund Centre conference attempted to address this by inserting a ground rule that participants should enable participants to make contributions by recognising and respecting differences of race, culture, class, sexuality, age, etc. However, with regard to equal opportunities, the contradiction remains that while the search method emphasises the need for participants to recognise and respect other people's right to their own opinion, it provides no guidance or recognition of the reality that other people's opinions can be bigoted and can actively inhibit full participation. If the search method is to be used for future consultations, it is important that such contradictions be resolved. Failure to do so will not only compromise the role of facilitators but may also end up reproducing and strengthening power relations through the search process itself.

Giving and getting

An undoubted strength of the search method of consultation is that it provides, through the ground rules, a very real bridge between the task of consultation is taking place – but within a participative framework. Care is taken to ensure that the process is in part-owned and directed by the participants themselves.

The level of involvement this demands can certainly raise expectations. One participant in my group, for example, felt drained after the first day and wanted "to have something concrete" out of the process. This raises the very real issue of how does the search method benefit the participants? What do they get out of it?

- For many people it was their first opportunity to get together with other service users and carers and share their experiences.
- People had the chance to see things "from the other side of the fence". For example, carers could understand what the issues were for users, and vice versa.
- Participants knew that the issues they had raised during the conference would be communicated to policy-makers and professionals by the King's Fund Centre.
- Individuals had the opportunity to put their views to members of the press.
- Significantly, for some people, this was the first time that they had been offered any information about forthcoming changes in community care.

In retrospect though, there were other additional ways in which the benefits to the participants could have been maximised and which would be most effective at a local level: because the search process is interactive, it has the potential to inform as well as to enquire. During the course of consultation, information could be made available to participants about services and facilities that can empower participants in their everyday lives. The need for consultation processes to examine and even to sell the benefits of consultation is also an important consideration in encouraging fuller participation in the first place. The search process can also be used to encourage users and carers to become more actively involved in consultation. Many are, understandably, somewhat sceptical of its value, fearing that their views will perhaps be listened to but not acted on. The search model should be able to demonstrate that consultation can be genuine, non-token, and worth doing.

From a facilitator's point of view, the advantages of using the search conference method have to be seen in a broader context. A considerable amount of work was undertaken both before and after the conference including consultation with community groups, and efforts were made to ensure that the conference facilities were appropriate to the diverse needs of the participants; participants were sent information about the search process and what to expect, and facilitators were consulted and briefed about their role. This level of investment meant that the actual facilitation of the conference was only a part of a wider process. Using the search method, therefore, has serious resource implications for any organisation, and it is important that these are addressed in the early planning stages. Otherwise the actual effectiveness of the search conference method as a means of consultation will be diminished or negated.

WHAT SOME OF THE PARTICIPANTS HAD TO SAY

Services

"If you can't get out of the house, how do you know what's available?"

"Public transport systems just aren't public!"

"I need flexible services so that I can be ill when I want to be ill!"

"I don't get any help with bathing my mother; social services say elderly people don't need baths."

"Sometimes I'd rather go without than go around like a beggar!"

"Why should we have to rely on charity – like the social club where we're 'restricted' to one glass of orange squash! Using charities is offensive to disabled people."

Campaigning

"Fighting is exhausting."

"Finding the right school for my son took eighteen months out of my life."

"Those who shout loudest get the attention and therefore get the most."

"Having higher expectations (of services) brings more hassles."

"You either have to give up – or get bolshy."

Carers

"Family 'carers' are disabled people too!"

"We're not selfless dedicated people – we've got no options. It's like being flung into a prison."

"Carers are taken for a ride."

WHAT USERS AND CARERS SAID

When users and carers talked about their lives and their experience of services, not surprisingly a range of different stories and viewpoints emerged reflecting people's individual circumstances. However, common themes were also evident indicating a shared experience among users and carers alike.

Worries about money were expressed as were widespread difficulties in being able to get out and about freely. Social security and transport came in for much criticism. Housing problems also came to the fore. Inadequacies in those service areas were causing great frustrations and, in some cases, considerable anger. For some people, these services (or lack of them) were having a greater impact on their quality of life than anything provided by the NHS or social service departments. In this respect, participants reinforced the importance of seeing 'community care' in its broadest sense.

In fact, users and carers share much in common with other marginalised groups in our society in terms of their experiences of negative attitudes towards them; low incomes; poor housing; unemployment; lack of "money in the pocket", and reliance on (frequently poor quality) public transport.

Participants from Black communities faced particular difficulties; people mentioned: the lack of services sensitive to the needs of different racial communities – for example, professionals who don't speak the user's or the carer's (first) language; residential or nursing homes where the resident's language is neither spoken nor understood; teaching of English signing in special schools which is of no use to Asian families; immigration problems resulting in family members living apart causing additional stress to that caused by having a family member with disability; instances of double discrimination (on grounds of race and of disability); and racism among some professionals.

Not all experiences recounted were negative or critical of current arrangements. Consultations on service developments taking place with users and carers in some parts of the country were welcomed. Some developments for carers were appreciated, particularly where counselling had been made available. Special transport schemes were proving helpful, especially where these enabled 'travel beyond the limits of the borough and where booking systems were flexible. Independent living schemes were also mentioned as a positive development enabling individuals to arrange their own packages of care and to employ their own care assistants. Several people mentioned the growth of the self-advocacy movement as a positive development which had changed their lives for the better.

When it came to how services were delivered, criticism came fast and furious. So often it seemed that services were being provided in ways that suited service providers rather than users or carers. Complaints ranged from asking for help and waiting ages for any practical response; receiving the wrong kind of help or getting it too late (particularly where equipment or adaptations to the home were concerned); having to book transport or respite care services well in advance. Some people felt that bureaucracy was on the increase, with more forms to fill in and more workers to see but no increase or improvement in what was on offer. A lack of co-ordination in service providing agencies means that you have to go through numerous assessments rather than a one-off. As a result, as someone described it, 'the bits often don't fit together'. Sometimes a service deficit in one area affects another part of a person's life. For example, you may, with help, get a job but if there is no accessible appropriate transport to get to work then you can't work.

Most people felt pessimistic about their future if nothing was going to be done to change the current situation. Life would be "bleak", "pretty grim" and "uncertain". There were fears that things would get worse, with more stringent means-testing during assessment, with more residential homes closing and with carers getting older and less able to cope as time went on. Thinking about the future was hard for many people; not only because the day-to-day existence of people with disabilities and of their carers is often exhausting but also because you may feel you have very little control over your present life so how can you picture a future?

Both users and carers were clear about the changes they would like to see. More choice, more consultation, more control over how resources are spent, more flexible services and speedier assessments of need – all of which were consistent with the declared intentions of community care reforms. However, they also wanted "more money in my pocket" and "basic services as of right" – requirements which will not be met by the reforms. Many were adamantly opposed to 'services on the cheap' and any increased reliance on charities who should only be providing 'the icing on the cake'.

When considering the government's plans for community care, there was considerable support for the proposals coupled with serious doubts that anything much would change because of government unwillingness to commit the resources required to make them work. There was also some unease about a possible return to Victorian times, with more pressure likely to be put on families and greater emphasis on charities. Considerable worries were expressed about how accountable the "new" model of community care will be as services will increasingly be provided by a range of different (often non-statutory) providers.

The prospect of case managers coming on the scene raised more questions than answers. People realised that this new worker could have a major impact on their lives, deciding what support they should receive. "What happens if they don't like me?" "Will I have the right to change my case manager?" "Will they be suitably qualified to work sensitively with people from ethnic minorities?" "Will it be just another professional to deal with?".

In the discussions, users and carers talked freely about their lives, their worries and their hopes. They spoke about their needs and the changes they wanted in a language, and with emotional intensity, bearing little resemblance to the way professionals talk about community care. Some users and carers felt that their experience and knowledge was not recognised for what it is – expertise. That expertise was not valued and too few people with disabilities (and carers) are in positions where they can influence the sort of services which people need.

They were keen to influence events, identifying ways in which they would work to make their views known and to press for change. They were aware of the time and energy required for this and appreciated that, for many people, campaigning for change was not realistic as they struggled with day to day living. Having the opportunity to voice their views was fine but only if, at the end of the day "someone was listening and acting on what they said". My main fear is that "all this will be a waste of time" sums up the feelings held by many at this consultative event.

WHAT DID THE SEARCH CONFERENCE ACHIEVE?

Search conferences are comparatively rare events and this particular conference for people with disabilities and carers was, we think, probably the first in the UK which brought together these two groups. Like any event which is breaking new ground, there were things which we could have done better – or differently – but, with hindsight, we felt that the conference had a number of unique benefits:

- We were able to bring together people with disabilities and carers when the more usual pattern is to hold separate events for these two groups.
- Carers and users were able to share their experiences and did understand each other's points of view.
- We were able to bring together people with different experiences of disability despite the fact that services are organised in ways with tend to divide them and keep them apart.
- The conference brought together people of different racial and cultural backgrounds – something which is still often considered too time-consuming and difficult to organise.
- We succeeded in our aim of finding participants who were not regular conference-goers and in enabling them to express their views.

- We were able to follow the basic search conference approach; we did not have any "speakers" or "experts", for example.

Although not exactly "achievements," a number of issues arose which we think are worth sharing with others who may be contemplating a similar exercise:

- The anticipated conflicts of interest between users and carers did not seem to arise. There was no clear-cut "carer's view" or "user's view". People have very different experiences and view the world very differently.
- Although people were wanting a better deal from services, they did not have the same views about how those services should be delivered. Some people were much more committed to integrated provision than others.
- Despite having a structured programme with five stages to be worked through, people still came with their own agendas. Some felt that they needed to express some powerful feelings about their lives and about the way they were treated, while others wanted to get on with the "agenda". These competing needs can be difficult to reconcile at times, and "differentness" can feel very threatening sometimes.
- Because participants were talking about their personal experiences, this could be emotionally draining or difficult at times. The search process does not really give people the time and space to deal with these difficult feelings.
- Although everyone knew the ground rules and had agreed to abide by them, it is still quite difficult not to disagree, not to want to interrupt other people to put forward your own viewpoint.

The main lessons to be learned from this conference are: that the search format offers a real opportunity for consultation to begin with the individual and his or her needs; that people with disabilities and carers can be consulted jointly; and that each can respect and value the other's experiences. We believe this model may offer a much needed opportunity to break out of the conventional and often ineffective mould of consultation which currently exists.

Appendix

Users Speak Out by Alison Wertheimer

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USERS SPEAK OUT

Users' voices are rarely heard. Alison Wertheimer listened as some of them gave their views on proposed changes in the community care White Paper

The Griffiths report, the subsequent White Paper, and the NHS and Community Care Bill have stimulated a wide-ranging debate on that elusive concept, "community care", but consumers' voices are easily drowned by the more powerful professional voices.

To provide a platform for consumers to voice their concerns about community care developments, the King's Fund Centre held a two-day search conference in June called "Your chance to speak out" for service users and carers; professionals were deliberately not invited.

With roughly equal numbers of carers and service users, the latter included elderly people, people with physical disabilities, sensory disabilities and learning difficulties, people with AIDS and people with mental health problems.

A number of carers and users were from ethnic minority groups, including some whose first language was not English, and although a few participants were experienced conference-goers, for many this was the first time.

The search conference ground rules look straightforward enough — putting them into practice proved less easy. people had come along with very different agendas, some needing to express pent-up feelings of anger and frustration, others wanting to work on less directly personal issues. Participants sometimes found it hard to allow others to speak without challenging or interrupting them. People with speech difficulties and those relying on the interpreters found it particularly hard at times to make their voices heard.

It soon emerged that a uniform disabled person's or carer's viewpoint does not exist: people were coming from very different places — literally and figuratively — and this could lead them to different conclusions.

Geographical differences meant that people who lacked a particular service and found it was routinely available elsewhere were frustrated.

MISMATCH

But many shared experiences and concerns. It is frequently assumed that the needs and wishes of carers and cared-for are very different — even mutually exclusive — and one or two participants did voice that dilemma.

For most people, though, the most difficult relationships were with groups not represented at the conference. Listening to participants talking about their experiences as service users, it seemed as if professionals and service users inhabited different worlds — a mismatch of perceptions, as one participant described it.

Although, predictably, many people received inadequate support, it was the way services were delivered which came in for particularly heavy criticism — stories of wasted resources, either because the wrong equipment was provided, or help came too late.

Waiting three years for a downstairs bathroom is bad enough, but when that person can no longer get to the bathroom by then because they are bedridden, that adds insult to injury.

Too often services are delivered in ways that suit providers, rather than recipients. At the least it can mean not being able to accept a last-minute invitation to go out because dial-a-ride has to be booked 48 hours in advance; at the worst it means a carer "not being able to be ill when I want to be ill" because the respite service for her handicapped child requires three months' notice.

Most shameful of all, though, are the service providers who ignore the users — who promise help but don't deliver it, who never reply to letters or return phone calls.

SOMETIMES POSITIVE

Despite these difficulties some people had more positive experiences, often resulting from their involvement in self-advocacy or other user groups. The services which people found particularly helpful were counselling for carers ("often seen as a luxury") and flexible special transport schemes ("which allow me to travel beyond the limits of the borough") — though by no means everyone had access to such services.

One or two participants had managed to negotiate individual care packages by using their own savings, enabling them to employ their own care assistants — but, again, they were a minority.

Participants were worried about the future: "bleak", "pretty grim", and "uncertain" was the general tenor of the feedback. For many, their already precarious coping strategies were threatened not only by uncertainties about future support services but by the prospect of ageing carers being unable to cope " "so you end up with two disabled people", as one person said.

Talking about what an ideal future might be like struck a more positive note. Interestingly, many of the contributions had an air of Griffiths-speak: "choice", "having control over how resources are spent on me", consultation", "more flexible services", and "better and speedier assessment of needs".

But other hoped-for changes revealed a parting of the ways — "more money in my pocket", basic services as of right", and "charities only to provide the icing on the cake" not "services on the cheap".

The discussions about whether the government's plans would actually help people can best be summarised by one person's comment — "lots of words and little flesh on them". Although there was considerable support for many of the White Paper's proposals, there was equally widespread agreement that proper implementation was unlikely because the government had realised it would cost too much.

Participants felt that a return to Victorian times was more likely with families expected to provide the care, for free, and charitable provision there as a backstop.

NEW BREED

Many of those present were particularly concerned about the proposed case managers: what sort of animal would this new breed of professional be? They realised that the case manager could exercise a considerable influence over their lives, in determining the level and nature of support they received from services. Many different concerns were expressed: "What happens if they don't like me?" "Will I have the right to change my case manager?" "Will they be suitably qualified to work sensitively with people from ethnic minorities?" Will it be just yet another professional to deal with?"

EXHAUSTING

Disabled people and their carers knew what they needed from services, but the problem was how to get it; how to get their hands on a share of the power and control over resources which other people currently held.

It was often difficult to find the energy to campaign for change; "fighting is exhausting" someone said, and the sheer effort required for day-to-day living leaves little energy for such activities, though they knew it was often "those who shouted the loudest who got what they wanted".

But even those who decide to become politically active find obstacles in their way — like the woman who decided to run in her local council elections but found that all the selection meetings for candidates were held in places she couldn't reach in her wheelchair.

Service users still have relatively few opportunities to express their opinions and little has been heard of their views on Griffiths and the White Paper. At the end of the two days, that was what concerned participants most — who would listen to what they had been saying, and if people did listen would it make any difference?

The White Paper made many fine statements about consultation and consumer choice. The proof of the pudding . . .

JRP

A Chance to Speak Out encourages health and social care agencies to adopt and adapt the Search conference method as part of their local consultations on community care. This report arose from workshops held in 1990 to consult service users and carers about community care.

Some of the topics covered in *A Chance to Speak Out* include:

- ➤ planning the Search conference
- ➤ advice on practical organisation
- ➤ reflections from a carer, service user and facilitator involved with the workshops.

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