Consultation with Carers
Good Practice Guide

by Barbara Keeley and Malcolm Clarke
I am pleased to endorse this valuable addition to the resources that help Government and independent organisations to respond to the views and needs of carers. I have been the Association of Directors of Social Services’ spokesperson on carers issues since 1997 and even during that relatively short period have seen a major sea change in statutory organisations’ approach to working with carers. Much of the stimulus for this comes from the National Strategy for Carers but, in my experience, also from carers and carers organisations. With this growing recognition for carers has come more subtle debates about recognising carers in our own workforce; about the moral and ethical issues of young carers and balancing the rights of disabled people and their carers. Perhaps most important of all has been the recognition of carers as co-workers and partners in service provision with a strong, independent interest in the shape of services provided for them in their own right and to support them. Working with carers is, now, an essential part of the life of a social services department or an NHS organisation, not an option. A tool like this is, therefore, very valuable in shaping ideas and best practice. Let’s hope this is a big step towards services that further recognise, empower and support carers.

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Introduction
Aim of this guide
This guide has been written to provide advice on the best and most effective methods of consulting with carers. It is aimed at those who provide, plan or commission services for either carers or the people they care for. It can also be used by carers, as a checklist on what to look out for and what to ask for when service providers are consulting with them.

This guide deals with consultation about the services available to carers and the people they care for, as a group. It does not deal with carers being consulted individually as part of an assessment of their needs as carers (although many of the principles of consultation are equally important in that area).

A question which is frequently asked of the national carer organisations is ‘What Works?’ in consulting with carers. The answer to that question is not a straightforward one as carers are a diverse group within our society. The purpose of this guide is not to present a completely prescriptive model, but rather to raise the issues which those undertaking or planning consultation should be aware of, and to give advice based on the practical experience of some of those who have undertaken successful consultations with carers.

In compiling this guide we have drawn upon some work already undertaken by other organisations. We have added substantially to this by illustrations of good practice that emerged from the results of the Carers Speak Out project, supported by Barclays, which was undertaken by The Princess Royal Trust for Carers in the first half of 2002.

What is “consultation with carers”?
We define consultation with carers as being a process which seeks the views of carers about the nature, extent and arrangement of services which are provided for carers and/or the people they care for, with a commitment on the part of those doing the consulting that they are prepared to consider making changes as a result of receiving those views.

Consultation is more than providing information about what changes are being planned for services (although effective consultation does rely on appropriate information being given to those being consulted).

We distinguish this definition of consultation from the more participative process implied by the term ‘involvement’. Many carers are involved with shaping local services. Their input helps service providers to identify priorities and formulate policy and to plan, monitor and evaluate services. However, a much wider group of carers is consulted about services and we feel that it is currently more desirable to improve that consultation practice. Adopting the principles of good practice in consultation would in any case also pave the way for more participative involvement of carers in shaping health and social care services. (For those who are more concerned with public involvement there are a number of useful guides already written on the topic and a list of these is given in Appendix 1).

Consultation with carers is not the same as consultation with users. Of course, carers have the interests of the person they are caring for at heart, and in many cases the views of the carer and the user may coincide.

Nevertheless, it should be recognised that both user and carer consultation are important principles in their own right. Carers have needs and views as carers which should be taken into account.

The importance of consulting with carers
We hope it is now widely accepted that carers have a right to be consulted about the services and decisions which affect them. We believe that such consultation is likely to lead to better decision-making by service providers, planners and commissioners.

The Government’s intentions for consultation and involvement of carers by service providers in the public sector were laid out clearly in the National Strategy for Carers. In describing the three strategic elements laid out in that Strategy, the document gave the following intention on involving carers:

“carers should be involved in planning and providing services”.

This was made more explicit by explaining how this fits in with wider consultation with service users or patients:

“The Government wants all organisations involved in caring to recognise that they can no longer have a focus just on the client, patient or the user. They must see the person needing care and support within the whole environment of their family, their neighbourhood and their community. This must include their carer or carers.”

So, consultation with carers should be seen as a ‘MUST DO’, as part of the expanded levels of consultation now expected of statutory service providers.
Looking for good practice in consultation
The Carers Speak Out project was one of the largest consultation projects with carers ever carried out in the United Kingdom. It provided a forum for carer consultation on carers’ needs, priorities and issues, to provide feedback to the Government on its UK Strategy for Carers. The consultation project offered the opportunity to reflect on the changes that have occurred for carers since the national strategy was launched in England in 1999, and on what changes still need to be made to improve the lives of carers.

The Carers Speak Out project combined different consultation methods to explore carers’ views. A postal questionnaire was sent, via PRTC Carers’ Centres, to over 8,200 carers across England, Wales, Scotland and Northern Ireland. Around 2,800 replies were received and this provided quantitative data on carers’ issues and needs.

Knowledge of carers’ issues and needs was further developed by the qualitative input from carers attending one national and eleven regional consultation events. These events brought carers together with senior professionals in social services and health and elected members from national and local government. All together they attracted an audience of over 1,400 carers, professionals and decision-makers. In planning their events, PRTC Carers Centres were asked to identify issues and good practice in consultation and to try out different or creative ideas in consultation.

The project has informed the production of this guide in two ways:-

- by identifying what carers themselves think of existing consultation practices, and how they think these practices could be improved
- by learning directly from the experience of organising and undertaking a large national consultation exercise with carers, using different methods of consultation.

The Carers Speak Out project has demonstrated that it is possible to do consultation well and that when it is done well, carers appreciate this and are only too willing to remain involved. We hope that this guide will make a positive and practical contribution to others ‘doing it well’.

Learning from experience – the need for good practice

Across the network of Princess Royal Trust Carers Centres, staff and carers are finding that much more consultation with carers has been taking place since the launch of the Government’s National Strategy for Carers in 1999. There are now very many demands from service providers for consultation with carers and many service providers are using Carers’ Centres to facilitate this consultation.

As we developed the Carers Speak Out project we found some carer organisations reporting that they and some of the carers they were in contact with have grown ambivalent and even cynical about consultation and involvement processes with statutory service providers.

The reason often given for this was not that carers did not want service providers to listen to their views and hear about their experiences. Rather the reason seemed to be that those who had experienced consultation and involvement with statutory service providers found the experience too often to be a negative one, due to poor consultation practice or lack of feedback about results.

This informal feedback from Carers’ Centres on how a number of carers were viewing consultation has been confirmed by recent research with carers on consultation. The Joint Futures for Carers Report looked at this issue for Scotland and highlighted the concerns of carers who were asked how they felt about consultation exercises they had been involved in. Carers were asked whether the agencies consulting them followed the good practice points detailed in the short checklist in the UK Strategy for Carers and in the National Strategy for Scotland’s Carers. The results gave cause for concern:

“What does emerge in many areas is a picture of weak or indifferent practice with consistent adherence and resourced commitment to good consultation principles the exception rather than the rule”.

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2 Joint Futures for Carers: Making Local Partnerships Work, Coalition of Carers in Scotland, 2002
3 The Strategy for Carers in Scotland, Scottish Executive, 1999
With regard to the NHS, the report also comments: “...significant numbers of NHS planning bodies never consult carers or their representatives when developing health plans and strategies important to carers and respond only partially when carers do express their views and needs, or not at all”.

The ‘Joint Futures’ report also outlines some of the poor or indifferent practices in consultation which led to the report’s conclusion about the need for improvement in practice.

Carers felt that, in relation to the timing and notice given for meetings, too little account was given to the pressures and strains that are typical in carers’ lives. In short, those consulting carers did not use carers’ time and good will wisely, despite the Government urging them to do so.

While carers felt that prompt feedback was also the most important of the good practice guidelines it was also felt to be one of the most widely disregarded of the guidelines.

**Dealing with consultation fatigue**

In planning their own consultation events for the *Carers Speak Out* project, a number of Princess Royal Trust Carers’ Centres also looked at how the problem of ‘consultation fatigue’ might be overcome. In planning their event the Bristol and South Gloucestershire Carers Centre, came up with the following checklist of actions to help avoid consultation fatigue among carers:

- Involve carers in planning the event
- Provide quality information to carers in a variety of formats.
- Start the day by reporting on how past consultation has had an effect on services for carers
- Have relevant professionals around throughout the day to listen to carers
- Allow time at the event for carers to express views.
- Link carers feedback to local or national strategy issues
- Provide feedback promptly after the consultation event
- Make the day an enjoyable experience for carers with time to socialise, have therapy sessions or gain new skills.

These good practice points and the many other points arising from the *Carers Speak Out* consultation events form the basis for the advice of consultation with carers that follows in this guide.
General principles for successful consultation
In reviewing successful practice in consulting with carers and listening to carers talk about problems they had encountered, some general principles emerged which we see as important as the building blocks for successful consultation.

**Successful agencies will:**

- **Be committed to the process**
  The organisation undertaking the consultation should be genuinely committed to the process. This means that you are undertaking the consultation because you believe that carers have a right to be consulted, and that consulting them will contribute positively to decisions about the development of services. It is also important that you are able and prepared to undertake the consultation properly and thoroughly.

  If your organisation is not genuinely committed in this way or if key decisions have already been taken and cannot be changed (whatever the outcome of the consultation) or if you cannot undertake the consultation properly, it is better not to do it all. Time is precious to carers. If you are not clear, then you may waste their time in what they perceive to be a sham consultation they are likely to feel more disillusioned and cynical than if there is no consultation at all. Sham consultation will also adversely affect your future relationships with carers.

- **Recognise the distinctive circumstances of carers**
  Carers have particular difficulties and circumstances, precisely because they are carers, which must be recognised. Consulting with them therefore requires a different approach to undertaking a general public consultation or a consultation with a particular group of service users. It will not be sufficient to simply replicate an approach or model which has been used for other groups, however successfully that approach proved with the other groups.

  What works in consulting with older carers may not work in consulting with younger carers and many other variations could be looked at for different groups. You therefore need to tailor the format of your consultation to the particular group of carers you wish to address.

  Anyone organising a consultation with carers should always remember that, generally speaking, it will be more of an effort for a carer to participate in the consultation than it is for you to organise their participation. They deserve to be treated with respect – As the National Strategy for Carers put it: “Remember that carers, who already give a great deal, are being asked to give more to help not only themselves but others. A little respect and recognition of their generosity in giving more on a wider stage goes a long way.”

- **Be clear what it’s about (and what it’s not about)**
  Before you start, it helps to think – What exactly are you consulting about? You need to be absolutely clear about this in your own mind and within your own organisation.

  If you are not clear, then you may not choose the best consultation method and approaches to gain the information you want, and the quality of the response you receive will be lessened as a result. Even worse, the carers you are consulting are unlikely to be clear, and may even be misled into thinking that the consultation covers issues which it does not. This may lead to subsequent cynicism and disillusionment.

  For example, something like “We are seeking your views on the services we provide for children with disabilities” will lead carers to believe that it’s a very general consultation not only on all aspects of the services currently provided, but also on the gaps in those services as well. If that’s what you really intend, then fine. But if it’s not, be more specific about what exactly you are consulting about e.g. “We are seeking your views on whether you would support the introduction of and use the services of a professional short break care service”.

  However, remember that it may be much more effective to consult about the issue or problem you are trying to address, than about a particular service development proposal, because the carers may have some ideas which you haven’t thought of. Thus the example given above might be further improved along the following lines “We are seeking your views on what types of service or support would best enable parent carers of children with learning disabilities to take a break”.

  Before you start your consultation, check whether carers have already been consulted about the same issues or service developments before. You should check this for your own organisation and for other service providers. Carers get tired of being consulted about the same issues.

- **Avoid jargon and don’t assume carers have specialist knowledge**
  When designing an information pack for a consultation event, a talk at an event or a questionnaire, take care to avoid using jargon and do not assume specialist knowledge on the part of the carers.

  It is difficult for many people to realise when terms they use everyday constitute jargon to other people. By ‘jargon’ we mean words or concepts which may be very familiar to the person using them but which are not understood by people outside that person’s organisation or work context. A further difficulty can be caused when information in a talk or in writing covers ground which is
irrelevant to those listening.

It can be dispiriting for those being consulted if jargon is used, making them feel excluded from understanding the content of the policy or service issue being discussed. Use of jargon or incorrect assumptions of knowledge held by your audience will also reduce the effectiveness of the consultation exercise. It is a good idea to get someone who is not involved ‘in the system’ (ideally a carer) to check out all your consultation materials to remove this possibility.

- **Always provide feedback, and be clear about outcomes and timescales**

  It is always good practice (as well as being polite) to let those who have participated in a consultation know what the outcome has been and what has or will change as a result of it. Feedback about the outcome of the consultation should happen as soon as possible after it has been completed. Further changes which have resulted from the consultation are likely to be on a longer timescale.

  It is important that you make it clear to the carers you are consulting exactly how and when the results of the consultation will feed into the decision-making process and how this may affect the way that services are provided. Although most carers are interested in what other carers think about an issue, feedback should ideally go beyond summarising carers’ views. Carers will be more interested in the impact those views have on decisions about services.

  Reports on the results of the consultation which are not clearly linked to the decision-making process may mean that the consultation seems like an academic exercise. Unless carers signed up to the consultation understanding that the research was for academic purposes rather than changes to service delivery they are likely to feel disillusioned and less likely to take part in future consultations.

  It is good practice to communicate all this to carers without leaving the onus on them to find out. For example, you could inform them of the results of the consultation when these are available, then inform them of any decisions about services made as a result of the consultation and, finally, inform them when those changes are actually implemented on the ground.

  This can then be followed up sometime later with an evaluation on how effective those changes have been. These principles should also apply even if no changes are made as a result of the consultation exercise and the people consulted should be given the reasons for this. Only if this is done will carers really feel that the exercise has been worth the time and effort which they put into it.

  Be clear and realistic about timescales for feedback. Although giving feedback may be only one of a number of issues you are dealing with (and perhaps not even the most urgent or important in your mind) it may be much more central in the minds of the carers, who may be waiting for the publication of the results of the consultation.

  Therefore, try to be as prompt as possible with the feedback, whilst also being realistic about timescales. It is better to have a longer anticipated timescale on which you can actually deliver, than raise expectations and fail to meet them.

  A good example of clear communication and combining a consultation event with feedback on previous consultations was provided by one of the Carers Speak Out events. At the event in Moray, posters giving feedback from earlier consultations were displayed as shown in the text box on the right.

  **You asked for...**

  Clearer more readily available information

  A worker for young carers

  Assessments of carers needs

  Flexible, accessible transport services

  **We provided**


  Regular newsletters for all carers on the Carers Register

  A Young Carers Support Worker – appointed October 2001 – to provide information, support and counselling

  The self assessment and full assessment forms – being revised by the Carers Forum

  Moray Assisted Transport Scheme – subsidised specialised transport, and buses through community transport

  **What should we do next?**

  This feedback showed that carers’ comments from earlier events had been acted on in specific ways. Carers attending this event could have confidence that action would result from points they made, where it was feasible to do that.

  At the Moray event, feedback was promised within six weeks. This initial feedback was sent, as promised, within six weeks in the form of a booklet. The booklet gave background information about progress on earlier consultations. It also summarised the responses from discussion groups at the event and highlighted local and national issues emerging from the day. It commented on progress already being made on these issues. Finally, comments on the event from carers were reported.
Choosing the method of consultation
Think carefully about the types of consultation methods you want to use. In particular, do you want to employ indirect consultation e.g. through a postal questionnaire, or direct face-to-face consultation e.g. by organising a consultation event? You can, of course, use a mixture of both approaches for any given consultation exercise. If you have the resources, there may well be advantages in doing so. The Carers Speak Out project used both approaches.

**Indirect consultation**
The advantages of indirect consultation are:
- it may enable you to approach a larger number of carers
- you will be able to get responses from carers who are unable or unwilling to come to a consultation event
- you will be able to get the views of each respondent over a wider variety of topics than is likely to be the case at a consultation event
- the responses will arrive in a more structured form and will therefore be easier to analyse.

**Devising a self-completion questionnaire**
Be very clear about exactly what information you are trying to obtain, and from which carers. Set up a reference/planning group to explore the areas to be covered. If possible involve some carers in this group.

Always take professional advice when devising a questionnaire. Self-completed questionnaires are usually structured, that is they use precise wording and most questions offer a selection of predefined answers. This makes them the most difficult to design well.

Questions which may seem clear and unambiguous to you, may not be so to those responding. Rotate your questions and the questionnaire format with a group of carers, preferably including older carers, to test ease of use for that age group.

Take professional advice about drawing up the sample of carers to be approached for the survey. It is very easy for those who are not qualified and experienced in this field to introduce bias into the sample frame.

Think and plan in advance how you are going to analyse the results, and take professional advice on this too. "Open-ended" questions, for example, are very attractive as a means of giving carers an opportunity to express their view in their own way, but can be complex and difficult to analyze.

Enclose a stamped or pre-paid return envelope for the questionnaire to ensure that carers don’t incur any postage costs.

Give carers the choice of either giving their name and address, with the possibility of further contact to follow-up particular issues, or of remaining anonymous.

**Direct consultation**
The advantages of direct consultation are:
- It enables a dialogue with carers, and between the carers themselves, which may improve the quality of the output
- It may be easier for carers to identify the things which are important to them, not just answer the questions you devise
- Many carers will appreciate the opportunity to meet professionals, decision-makers and other carers face-to-face, which should improve relationships between them
- It enables the event to be used for other things e.g. providing information to carers, and other activities for them to participate in
- It offers an opportunity to recognise carers and directly thank them for the work they do.

There are several different options for direct consultation including interviews using semi-structured or unstructured questionnaires or events such as focus groups, workshops, conferences etc.

This guide focuses mainly on consultation events or conferences containing workshops or discussion groups to consult with carers, as this is a format which was used successfully in the Carers Speak Out project.
Planning a consultation event
The importance of planning ahead
You need to leave plenty of time to plan the event and publicise it. It’s a good idea to produce a project plan, with timescales, allowing the odd extra day for problem solving, dealing with the unexpected and to reduce anxiety for those running the event. It is difficult to set up an effective event in a rush.

If possible, involve some carers in the group planning the event – they may have perspectives or think of things which wouldn’t occur to you. At the very least, talk to carers before the event to determine what issues should be included in the programme and what interesting or informative activities they would like included in the day.

Plan a run-through of what will happen on the day with staff, facilitators volunteers and venue staff so that everyone knows what they are responsible for and how any problems will be tackled. Ensure that the venue staff understand the aims of the event and the importance of making sure that carers feel valued and well looked after.

Build in extra minutes between sessions in the programme to give people time to move between rooms without any stress. Those who are co-ordinating the event should all work to keep the atmosphere as informal, relaxed and good-humoured as possible.

Invitations to the event
Government guidelines on consulting with voluntary and community organisations recommend allowing 12 weeks in total for consultations4. When working on consultation with carers there are good reasons to allow this sort of timescale.

Give plenty of notice of your event. Remember that carers need time to make appropriate arrangements for the person they are caring for. For this reason many carer organisations give carers 2-3 months advance notice of dates for events. At that stage carers may not know if they will be able to attend, so more details should be circulated 6-8 weeks before the event, when carers can be asked to book for the event. Ensure that it is clear to carers that you will meet costs of alternative care and travel to enable them to attend.

Carers do not usually have much ‘free time’ to read documents, but will want to prepare themselves to contribute fully to the event by reading the information for the event, so this needs to be sent out well in advance. If they are representing a group or organisation, they may also need time to consult the people they represent. As many carers groups meet monthly, most carer representatives would need to be asked at least six weeks before the event to give input from their carers group.

Including a personal message from a carer’s representative as part of the invitation to the event may help to encourage attendance. This would help both to emphasize the ability of carers to get involved in consultation in order to improve life for themselves and other carers, and to ensure that carers felt ownership of the consultation event. It would obviously be particularly appropriate to do this if carers have been directly involved in planning the event.

Choose a suitable time and venue
Carers often find it difficult to get to meetings. Choose starting and finishing times which recognise their needs and difficulties. This is something on which carers themselves are best able to advise, but in general terms you should start later and finish earlier.

Take care with the choice of venue. Among the factors to take account of here are:-

- Geographical location: choose a venue which is central and convenient for carers to get to, taking account of public transport systems as well as road access.
- Access: the building should have good access for people with a disability including wheelchair access, hearing loops and clear signs in large print
- Layout of the building: choose a venue which suits the purpose of your event. If you want to have ‘break-out’ groups, make sure that the building can accommodate these comfortably. Effectiveness can be greatly reduced if groups have to be squashed into rooms which are too small, or have acoustic problems because they are sharing a room with other groups. The layout and acoustics in certain types of room which are used for consultation events, e.g. council chambers, committee rooms or theatres can be quite intimidating. A layout which intimidates people or makes it hard for them to speak may deter them from contributing as much as they would do in a different layout.
- Standard of the facilities: the venue should have a welcoming environment and high-quality facilities. In general, carers get fewer opportunities than others to

Planning a consultation event

get out and attend events. Some carers may be looking forward to your event for this reason. Too many events are spoiled by poor quality surroundings such as draughty halls or places with bad acoustics or uncomfortable chairs.

Provide good and clear advance information
Well in advance of the event, those people booked onto it should be sent a participant’s pack. The pack can be sent when confirming the carer is booked on to the event. This must go out at least one week before the event but preferably 2 to 3 weeks in advance. The pack should include:

- joining instructions and directions
- the timetable for the day
- a clear statement of what results you want from the consultation event
- relevant information (e.g. background reading or a discussion paper) on the subject of the consultation
- information relating to any discussion group the carer is to be in. This could include some questions to help and encourage the carers to focus on the issues they will be discussing.

This material should be accessible to all those attending i.e. it should be in clear, plain, jargon-free language (preferably checked as such by a person with good skills in clear writing) If necessary, and appropriate, versions of the information should be provided in other languages or other formats (such as large type).

Provide support to carers to attend
Alternative care – it is essential to offer to provide or pay for alternative support for the person the carer normally cares for. Make sure that both the carer and person being cared for are given the opportunity to discuss and choose between a range of services so they both feel valued.

Expenses – you must offer to pay fares and any other costs that a carer will incur in helping you. For example, a carer looking after an elderly parent who has a school-age family will need to have costs covered for childcare for the children coming home from school as well as the alternative care organised for the elderly person being cared for.

Payment systems – you should have systems in place to allow you to order train tickets, etc, in advance or pay substitute care providers directly, because many carers will not be able to afford to meet costs prior to you reimbursing them. If you pay expenses in advance you should avoid giving cash if to do so would affect the payments to carers who are on benefits. In such circumstances vouchers, train tickets, etc, are preferable.

Transport – Consider laying on transport such as taxis or minibuses, direct to the venue, for all those carers who need it. Doing this will save carers time.

Target particular groups of carers
Think about which carers you would like to attract for the particular objectives of your event. In particular, try to attract carers who might not normally attend such events, the so-called “hidden carers”. These are people who do not even think of themselves as carers. Your invitation to the event should give a definition of carers which will highlight the people you are trying to consult.

Bringing in unknown or hidden carers to an event is likely to require extra effort and resources. You could advertise the event through taking an advert in the local press or on local radio as well as advertising the event widely through all relevant statutory and voluntary agencies and professional networks. It may also be appropriate to consider innovative ideas about where and when the event might be held to reach those carers whose voices are not being heard through existing channels and more conventional consultation methods.

An example from the Carers Speak Out project is a consultation event organised by Suffolk Carers at the Suffolk Show. The show is an annual event which attracts people from rural areas and farming communities, and to which special buses are laid on, enabling those who don’t usually have access to public transport to attend. The consultation took place in a prominent site at the showground, opposite one of the events rings, and next to the Disability Centre. Colourful banners and posters were designed to catch the eye and invite people into the Event, which was sited in an open-fronted marquee.

Publicity had been used to alert carers to the event – it was listed in the Show catalogue, and a press release sent to the county newspaper. There was an item about the consultation on local radio with an interview from the event being broadcast live on the first day. This event helped Suffolk Carers reach out to 87 carers, many of whom had not previously been in contact with the carers centre.

Think creatively and innovatively about how to reach your own local carers.

Consulting with carers in rural areas presents particular challenges. In organising consultation events in such areas you will need to think about the fact that carers find it difficult to travel far to get to meetings.

For example, in order to make the consultation venues more suitable for the carers attending, one of the Carers Speak Out events in rural North Wales was held in five different locations and transport was offered for carers to get to the event.

You may need to adopt a specially planned approach to encourage attendance from carers from ethnic minorities, including making event material available in appropriate languages, offering translation services and displaying sensitivity to cultural differences in such areas as the...
provision of food and other activities during the event.

For the Carers Speak Out event run by Bristol and South Gloucestershire carers centre, the centre worked closely with an Asian voluntary organisation to make the process accessible to the Asian carers they work with. Staff from this organisation and the Carers Centre’s own Urdu speaking worker were responsible for contacting Asian carers, explaining the day and dealing with any difficulties the carers had. Once carers had booked onto the event, staff also contacted them to work through the participants pack with them, and to give them any other information they needed.

Make the event attractive and enjoyable

A consultation event for carers shouldn’t be boring for participants. Try to avoid running the event in the ‘traditional’ meeting-type format.

Given the effort necessary to arrange alternative care and transport needed for the carers to attend you could use the chance to make part of your event enjoyable for carers. This would be very important for carers with the heaviest level of responsibilities who do not get many opportunities for a break from caring.

In order to recognise this and the generosity of carers in giving their time to the consultation event, several of the Carers Speak Out events organised extra sessions of relaxing or informative activities for carers. These included such activities as aromatherapy, reflexology, massage, sessions covering soft furnishing, floristry, art and craft, surfing the net, tai chi and shiatsu. Comments from carers showed they felt that these activities gave the event balance and made the day enjoyable:

- If the consultation is a whole-day event, with lunch being provided, you should make the lunch itself enjoyable by providing a good standard of food in attractive surroundings, and allotting a reasonable time in the programme for the lunch break so that people are not rushed. Carers need time to relax and chat to each other and read any information which you have given them.

The organizers of the London Forum of Carers Speak Out consultation event held the event in a good standard of hotel with a live jazz band playing during the lunch hour (both of these were negotiated at discounted rates). This helped to make the day as informal and relaxed for carers as possible, which had been one of the aims of the event.

Other ways to make the consultation event enjoyable which were tried successfully during the Carers Speak Out project were the use of drama performances and combining the consultation with an Information Fair aimed at carers.

The Carers Speak Out consultation at Moray was combined with giving information to carers at the event through an Information Fair and giving feedback on previous consultations at the event. The feedback was given through posters but also through a drama performance.

An earlier consultation had highlighted the need for better support for young carers and action had been taken through the employment of a young carers support worker. To highlight the work being done, a drama performance was given at the Moray event by Moray Young Carers working with the Out of Darkness Theatre Company. This was useful in two ways – firstly, in using a different method to give information and secondly in using a drama performance to enhance the consultation event.

Get the decision-making managers there

It is a good idea to use a consultation event to bring decision makers and planners from statutory service providers into direct contact with carers. This could include: Members of Parliament; Members of the Scottish Parliament, Assembly Members, local councillors particularly Executive Members; Local Social Services Directors and managers, Social Services professionals, Local NHS Trust Board members including non-executive members, NHS Managers and Professionals.

At many of the Carers Speak Out events, the involvement of health and social care professionals gave a chance for information exchange, sharing of ideas and the chance for professionals to listen to carers. In addition, the involvement of decision makers from national and local government allowed carers to ask questions about policy and strategy decisions and influence thinking on possible future changes to improve carers’ lives. These direct contacts led to some lively question and answer sessions, and were seen as a key aspect of making many of the events a success. It was also useful for those who make policy to receive such direct input on how policy is working out in practice.

Recently there have been major changes in the structures and decision-making processes of both the NHS and Local Government and Devolved Government in Scotland and Wales. At times of such change affecting health and social care services, it is particularly important that agencies from the new structures are involved in consultation with carers. This can give them an opportunity to explain the new structures, and how they impact on services for carers. For instance, carers need the chance to be informed about new developments such as Patients’ Advice and Liaison Services (PALS) and Patient Forums, both mechanisms designed to find out the views of patients and carers.

Consultation with Carers
Ways to run effective workshops and discussion groups
To improve the quality of outputs from a discussion group at a consultation event, it is important for both facilitators and the carers participating to be clear about the format of the discussion and to have a structure for the discussion to follow. Carers are consulted so that their views can be gathered and reported, to make an influence on policy and strategy. Gathering and summarising the input from discussions is more straightforward with a well-structured discussion session.

It is a good idea to assign two people to each group – one to facilitate the discussion and one to take notes, to ensure that comments from carers don’t get lost. It also may be useful for each discussion group to have a handout which gives relevant information and questions to structure the discussion, which may be devised by a planning group talking through various possibilities.

A useful format was devised for the Northamptonshire Carers Speak Out consultation event. A short initial discussion was planned, to help the discussion leaders to get to know their group. A first question was posed to start the discussion and help the carers focus on the discussion topic. Two further specific questions on the issue were then asked (in this case, Training).

Training for Carers
Discussion question: What are the benefits of obtaining skills and knowledge to support you in your caring role?
Consultation Question 1: What type of training would have helped or could help you in your caring role?
Consultation Question 2: Who else do you feel needs informing or training about the caring role?

 Allocate enough time for discussion – a consultation event should allow carers to be heard and to feel they have been listened to. Take care to give ample slots in the timetable for the discussion group sessions. Try to avoid sessions overrunning, which then eats into the time allotted for discussion. It is also important to think about the physical configuration of the group for the discussion. For example, the discussion groups might operate with all participants sitting at round tables to allow carers the same chance to talk and be listened to.

Using peer consultation methods with volunteer carers
At the Suffolk Carers Speak Out events, 21 carers were involved as volunteers guiding participants through the four activities in the consultation. After the event, the volunteers involved said that they felt that they had been able to “give something back” through helping in this way. Using volunteer carers may have helped the carers being consulted to have felt more confident and comfortable with the consultation. Volunteer carers who helped with the consultation were also able to have a day out at the Suffolk show to thank them for their help.

An effective mechanism should be decided in advance to record the points made by the carers, and the conclusions reached by the group. Flip-charts, cards, or post-it notes may be used for this purpose, the last two providing a flexible way of recording ideas and possible solutions outside the subject of the discussion. Facilitators can collect the cards, post-it or flip charts, and produce summaries of key issues identified for feedback to the whole conference. Keeping a written record assists input into the policy-making and planning processes.

Cards or post-it notes can also be used to give carers at the event a different way of raising issues. In case any carer is not able to put their point in a discussion group, due to lack of time or not feeling able to put the point verbally, they can be invited to add further points by writing them on a card or post-it note for inclusion into the feedback process.

If possible, have a carer or carers summarise the feedback on main themes, if there is a session for this on the timetable. There should be support from those who have run the discussion groups to facilitate carers doing this.

Stick to the timetable, but make sure it gives adequate opportunity for carers to participate
Making sure the consultation finishes on time will help carers to meet their transport arrangements and get back home in time to take over from the respite care or sitting service. Carers might feel embarrassed or annoyed if they have to leave the event before it has finished.

Sticking to the timetable is difficult during consultation events – bear this in mind when planning the timetable to be sure that you do not overfill the day and then have sessions overrun. Consultation events need firm chairing to make sure that speakers do not overrun and that sessions start on time.

Having said that, it is important to ensure that the timetable gives carers adequate opportunities to make their input. Those who organize events probably go to meetings or conferences much more often than carers do, and may not feel particularly upset if they don’t get the opportunity to make their point. Many carers, however, will see a consultation event as an important, perhaps unique, opportunity for them to say something which is very important to them. Therefore, leave plenty of time for questions and contributions, even if this means cutting down the time taken for presentations or talks by the principal speakers.
Useful publications on public involvement

- **Asking the Experts – A Guide to Involving People in Shaping Health and Social Care Services**, Community Care Needs Assessment Project March 2001
  
  Available from CCNAP, Health Place, Wrawby Road, Brigg, N. Lincs DN20 8GS 01652 601110 or on-line at www.ccnap.org.uk


- **Patient and Public Involvement in the new NHS**, Department of Health, 1999


- **Involving Users – Improving the delivery of local public services**, Service First, Cabinet Office, March 1999
  
  Available from Cabinet Office, Horse Guards Rd., London SW1P 3AL

- **A Guide to Public Involvement for Health Services in Leicester, Leicestershire & Rutland**, Leicestershire Health Authority 2000

- **Listen Up! Effective Community Consultation**, Audit Commission 1999
  
  Available from Audit Commission Publications, Bookpoint Ltd., 39 Milton Park, Abingdon, Oxon OX14 4TD

- **In the Public Interest: Developing a Strategy for Public Participation in the NHS**, Department of Health 1997

- **Community development and involvement in primary care – a guide to involving the community in COPC**, Kings Fund 1997
Carers Speak Out Project

The Regional Consultation Events
Between February and June 2002, eleven regional consultation events with carers were run as described in this section. A national consultation event was also held on June 14th 2002. The events attracted a total attendance of around 1,450 people including health and social care professionals, decision makers and over 1,000 carers.

These events were chosen to provide a mix of different settings for carers and with different types of carer being invited. At many of the events some aspect of the day was designed to recognise carers’ contribution to the consultation and to thank them for giving up their time for the consultation.

1. Carers involved in strategic planning in Northamptonshire
On 15th February 2002, PRTC Northamptonshire Carers ran the first event in the Carers Speak Out programme, at the Diamonds Conference Centre, Irthlingborough, Northants. The event aims were two-fold. Firstly, to consult with carers to inform the Carers Speak Out project. Secondly, event organisers wanted the consultation to identify the issues and needs of carers in Northamptonshire as input to the Northamptonshire Carers Strategic Plan for 2002-5.

Invitations were sent to 250 carers and among these it had been decided to target parent carers, as they had not been involved much in consultation previously. 160 people attended including 111 carers. Around one quarter of those carers attending were working carers and over twenty percent were in the age group 30-44 years.

The good practice that came from the event included:
• Event planning – following a checklist of good practice points
• Developing effective briefs for workshop facilitators and participants
• Giving feedback on earlier consultations throughout the event and providing feedback after the event within a short timescale

which helped to structure discussion group sessions and to gather and summarise the input from carers
• Making the day enjoyable – running activity groups for carers including “pampering” such as aromatherapy – to make the day enjoyable as well as productive.

The summaries from the discussion groups were fed into the process for formulating Northamptonshire Carers Strategy plans for the next three years. Following the event, two local MPs have increased their involvement with carers locally. One MP ran a surgery at the Carers Centre and the other MP met with centre staff to get an update on local carers’ issues.

2. Contacting new and hidden carers in Moray
The Princess Royal Trust, Moray Carers Project is a relatively new project formed in early 2000 to look at identifying the needs of carers and look at ways in which they could be addressed. The Carers Project is in touch with over 800 carers out of an estimated 12,000 adult carers in Moray.

Contacting further carers is therefore a key priority for the project. In 2000 and 2001 the project had run an Information Fair for carers.

On February 27th 2002, Moray Carers Project combined their Information Fair with a Carers Speak Out consultation event. Open invitations for carers to attend the event were circulated to everyone on the project’s carers’ register and all organisations from the voluntary and statutory services known to the project. In total two thousand invitations were circulated. Total attendance at the event was 270 people, including 170 carers.

The good practice that came from their event included:
• Involving carers for the first time and including them in the consultation
• Making the day memorable – including a drama performance in the event.

Through their very wide circulation of open invitations to the consultation event, Moray were able to include in their event a number of carers who had not previously been in touch with a carers support organisation. Because they had combined the consultation event with an information fair on services of benefit to carers, this also made the event attractive to a new audience.

3. Professionals Listening to Carers in Bridgend
A Carers Speak Out conference was held at a hotel in Bridgend on 12th March 2002. A feature of the conference was that a network of 10 organisations had come together to deliver the event. These included the Princess Royal Trust Carers Centre Bridgend, the Young Carers Project, Carers Wales, and other local voluntary and statutory organisations. As well as contributing to the national consultation project, the Bridgend event allowed local carers to focus on changes they would like to see in local services.

Over 60 people attended the event including 42 carers. A third of the carers were making their first contact with the Carers Centre. Two Young Carers also attended and talked about their individual experiences.

Eight chat groups were organised to allow small groups of carers to identify ways in which the quality of life could be improved for carers. Professionals attending the event could listen in these groups and over the long lunch break scheduled for the event. This proved an invaluable way of informing the local organisations about carers’ views while giving carers a chance to relax and enjoy the lunch.
An additional bonus from the day was that the carers present decided to form a new branch organisation in Bridgend to enable ongoing communication with all the agencies involved and to continue to advise the Carers Centre of local carers’ needs.

4. Planning to overcome consultation overload in Bristol and South Gloucestershire
On 25th March 2002, the Princess Royal Trust Carers Centre Bristol and South Gloucestershire held their Carers Speak Out Consultation Event for carers. The Carers Centre supports carers involved in work on policy issues and carers involved in a large number of advisory groups to service providers. At that time carers were heavily involved in the implementation of the National service Framework for older people. The centre staff felt that this change agenda was very large – in fact there were too many planning groups for them to field and support carers to them all.

The Carers Speak Out project offered the chance to combine the aims of the national consultation project with the local aims related to the work of carers on the implementation of the National Service Framework for Older People. The event provided the chance to enable a larger number of carers to engage directly with the work and plans. It also provided a constituency and manifesto for carer representatives on advisory groups.

The event was attended by 120 people, with around 90 of these being carers. The event had been targeted at older carers or carers of older people. All the carers at the event were over 50, with most being over 60 years. Most were caring for an older person but some of the carers in their 60s and 70s were caring for an adult son or daughter.

The good practice which came out of this event included:
• Taking specific steps in planning the event to overcome the barrier of consultation overload among carers being consulted
• Developing ways in which carers could have ownership of the event
• Giving carers the chance to get their thoughts together before the event by sending out information and questions in a participants pack
• Support for carers to access the event, including planned support to help Asian carers participate
• Providing full feedback in a report to those who participated.

5. Focussing the consultation for the local context in the North East
On 21st March 2002, six Princess Royal Trust carers’ centres in the North East came together with two independent carers groups to run a Carers Speak Out consultation event.

The good practice points which came out of the North East regional event were:
• Focussing on a specific consultation agenda of relevance to carers locally
• Effective workshop planning with briefing materials sent in advance and a presentation on key points before the discussion.
• Bringing key service providers from both social services and health face to face with carers affected by their strategies.

The focus of the North East regional event was older carers or carers of older people. There was a strong reason for taking this theme in this location. Economic changes in the North East region have led to an intensifying of the national trend towards an ageing population. This is notable in mainly rural County Durham, where traditional heavy industries have largely disappeared and many younger people have moved away to find work.

Among older people living in the area there are high levels of work-related disability or limiting long-term illness relating to previous work in the pits or iron works, with strokes and heart disease being particularly prevalent.

Also, with fewer young people remaining in the area, caring for those older people who are ill or disabled tends to fall mainly on older family members.

The North East regional consultation event was attended by around 100 people, with 60 of them being carers. The Carers’ Centres and carers’ projects in the North East ran the event with involvement of two local Primary Care Trusts and one county Social Services Department.

6. Reaching out to carers in rural areas in North Wales
In organising a Carers Speak Out consultation in North West Wales, local Princess Royal Trust for Carers Outreach Services had to think about the fact that carers in rural areas find it difficult to travel far to get to meetings. In order to make the consultation venues more suitable for the carers attending, the Carers Centre staff planned their event in 5 different locations.

The five events in North Wales took place on weekdays between Tuesday 7th May and Monday 13th May 2002, at hotel venues in Cricieth, Caernarfon, Ynys Mon, Dolgellau and Conwy. The numbers of participants varied from 25 to 48, with a total attendance of 180 people across the five events, including 125 carers.

The good practice which came from the North Wales events included:
• Making the event inclusive for carers in rural areas
• Bringing decision makers and planners into direct contact with carers via the consultation event.

In North West Wales the Princess Royal Trust Carers Outreach services cover a wide area run from bases in Bangor, Porthmadog, Holyhead and Colwyn Bay. In planning their Carers Speak Out event they chose to run five separate consultation events at five venues which would be accessible to local carers.
Appendix 2

By choosing accessible venues and by offering respite care to carers and transport to get to the event, event organisers felt carers would have more chance of being able to attend the consultation events. Languages were also an important issue at the North West Wales events – in the rural areas over 80% are Welsh speaking so the organisers planned to respond to carers in the language of their choice.

Participants were encouraged to speak in Welsh if they wanted to do so and translation facilities were provided for non-Welsh speakers.

The attendance of carers from rural areas at the events was excellent – 87 carers came from rural areas out of the total of 125 carers. It was clear from the workshop discussions that the events had also attracted carers who had not been in touch with the Carers Outreach services previously.

The North West Wales events had been planned with the aim of bringing decision makers and planners from statutory service providers into direct contact with carers. This aim was met very successful across the Carers Speak Out events.

Those involved with the five events included Members of Parliament, Assembly members, Councillors including an Executive Member for Social Services from the County Council Directors and Assistant Directors of Social Services, Social Services professionals, Health professionals including a Health Trust Consumer Officer and a Quality Manager, a Health Promotion professional, a Hospital Discharge Co-ordinator and Occupational Therapists.

This direct contact led to some lively question and answer sessions. It was also useful for those who make policy to have such direct input on how policy is working out in practice. A number of positive suggestions were made which should lead to local and national action.

7. Encouraging good practice in consultation in Northern Ireland

On 9th May 2002, 68 carers gathered at Belfast Castle with professionals from some of the major public bodies that have most impact on their daily lives as carers. The context of the event was for carers to highlight and encourage good practice in recognising their rights and responsibilities, following new obligations made on public bodies by Section 75 of the Good Friday Agreement.

Section 75 of the Good Friday Agreement commits statutory bodies to achieving much better practice in implementing equality of access and equal rights and treatment for all sections of the community in Northern Ireland. The Carers Speak Out event focussed on what this would mean for carers and encouraged carers to highlight their needs.

The consultation event had aimed to attract some high calibre speakers to attend and both talk to and listen to carers. Those attending included the Chief Commissioner for the Equality Commission, the Ombudsman for Northern Ireland and a representative from the Office of the First Minister and Deputy First Minister for Northern Ireland.

At the start of the event a carer made a strongly personal passionate and moving speech on her own experience. As well as a chance to speak out and to hear from the speakers from public bodies, carers at the event were able to attend a workshop on assertiveness and to enjoy the setting and hospitality of Belfast Castle.

8. Using a different style of event for carers in Wandsworth

On Saturday 11th May 2002, the Princess Royal Trust Carers Centre in Wandsworth ran a consultation event particularly aimed at groups of carers who had not been involved in consultation events or who were feeling “consultation fatigue” with the usual structure of events.

The good practice which came form this event included:

- Holding the consultation event on a Saturday, to enable different groups of carers (including working carers and young carers) to attend.
- Providing a crèche so that parent carers could attend. The crèche workers had experience of working with children with special needs or learning difficulties
- Enabling carers to express their views in different ways and to have fun through the use of drama, as a consultation method
- Recording the event in pictures drawn by a graphic artist.

To encourage young carers to attend, the Carers Centre worked with the local young carers’ project. This had an additional benefit for the centre’s work with carers as they had wanted to forge links with the young carers’ project to improve the transition of carers between the project and the Carers Centre at age 18.

In order to bring new and hidden carers into the event, it was important to publicise the event widely. This was done through newsletters and mailings but also through bulletin boards and information stands at GPs surgeries and through the local press. Publicity gained through the local press was particularly effective as the press were interested in publicising a different style of event, being run using drama and graphics.

On the day, 55 people attended the event including 39 carers. Having the event on Saturday meant a much smaller event than those previously run by the Carers Centre, but it also meant that very different groups of carers could attend. It also gave the organisers scope to try out a different style of event.

The use of drama and pictures to record carers’ views and comments also worked very well. On the day carers of all ages and different
9. Reaching out to contact carers in urban areas – West Midlands

On 17th May 2002, the Princess Royal Trust Carers Centre in Sandwell coordinated a regional event for the West Midlands. The event covered carers in a large part of the local urban area, covering the four local authority areas of Sandwell, Dudley, Wolverhampton and Birmingham.

The Carers Centre in Sandwell (called CARES) had brought together a steering group to plan the event and this was formed from a mix of local authority staff working with carers and staff from carers organisations.

The good practice which came from this event included:

- Reaching out to new carers to attend the event
- Presenting carers with information on local authority practice in consultation across four different areas and inviting carers feedback on the practice
- Good support to carers attending the event, including a workshop facilitated in different Asian languages for carers whose first language was not English
- The organisations which planned and ran the Carers Speak Out event in the West Midlands had a concern about “consultation fatigue” in their areas. They wanted to use the opportunity that running the consultation event offered to reach out to hidden and new carers to involve them in the consultation.

The consultation event was advertised to carers in the local press in the West Midlands. A hotline was set up so that carers who responded to the advertisement could book places at the event. It was planned to hold the event at a Midlands hotel which was accessible both to all motorway junctions and to public transport.

Over 110 people attended on the day, including 82 carers. A substantial number of the carers attending the consultation event had not previously been in touch with carer support services. These carers were able to be involved in the consultation and hear about and make contact with carer support services for the future. Time was set aside at the event for carers there to complete the Carers Speak Out survey questionnaire. A quick analysis of these showed that over half the carers completing the questionnaire had not been asked previously for their views about services.

The West Midlands event was held at a comfortable and accessible venue. A good lunch was provide across a long lunch break and carers were then given time (with support if they wanted it) to complete a survey questionnaire. A specific workshop was held at the event for carers whose first language is not English. Two staff supported this workshop with translation and the discussion was run in three different languages.

Each carer attending the event was presented with a pack including a Carers Diary, with useful information for carers. As many carers attending were not usually in touch with carers’ support services, their travel expenses were reimbursed on the day.

10. Consulting with carers across London

The theme of consultation with carers was also taken up at the London Carers Speak Out event held on 17th May 2002. This event was planned and coordinated by the London Forum of Carers, a pan-London group consisting of carers from across London as well as 45 carers’ organisations including The Princess Royal Trust for Carers and Carers UK.

The focus on consultation with carers had been one of the objectives set by the Forum in its plan for 2002-3. The aims of the Carers Speak Out event were:

- to explore in detail the problems of and good practice in consultation with carers
- to come up with recommendations that could feed in to both a London-wide carers’ strategy and the planning of services both locally and regionally
- for carers attending the event to have a good and enjoyable time

The event was attended by 160 people, including around 130 Carers. Senior managers and professionals from the Social Services Inspectorate and the London Health and Social Care Region were involved in the event, as well as the Chair of the Greater London Assembly. Some of these participated in a panel discussion on good practice in consultation.

The good practice points that emerged from the event were:

- Having a planning group for the event that consisted mainly of carers and former carers with support from professionals. This was empowering for carers and made effective use of the variety of skills.
- At the event, discussion groups of carers were at round tables, with facilitators. This proved to be extremely effective
- Key sections of the plenary sessions-the introduction, feedback on carers’ discussion themes, and the final summing up, were all done by different carers. Evaluations of the event demonstrated that these sessions were the highlights of the event.
- Clear recommendations and action points emerged which are being adopted as proposals to service providers and commissioners across the region.
- As well as being productive, the event was kept as informal and
enjoyable as possible and carers found the event fun.

A clear set of recommendations on good practice in consultation was produced from the event. These recommendations went forward to various London bodies that commission or provide health and social care services. Carers across London then planned to campaign for the acceptance of the recommendations at both local and regional levels.

11. Attracting ‘harder to reach’ carers in Suffolk

On 6th and 7th June 2002, Suffolk Carers ran a Carers Speak Out consultation event at the Suffolk Show. Suffolk Carers already has well-established routes for consulting with carers known to the organisation, through their database, newsletter, their 34 Carer Support Groups across the county, and their on-line forum, Carers Voice.

With this level of involvement, Suffolk Carers felt that the carers they were already in contact with could suffer from ‘consultation fatigue’. They felt that they should try to attract carers whose voices were not being heard through existing channels and more conventional consultation methods. They saw the Carers Speak Out event as an opportunity to reach carers who were not already in touch with them and who may not even think of themselves as carers.

In Suffolk, many of these ‘harder to reach’ carers live in rural areas. The Suffolk Show is an important annual County event, attracting people from farming communities and rural areas. Special buses are laid on, so those who don’t usually have access to public transport can attend.

The good practice points which emerged from this event included:
- Reaching out to ‘harder to reach’ carers
- Using peer consultation methods to involve volunteer carers in running the consultation process
- Devising simple, quick and enjoyable participation activities

Publicity had been used to alert carers to the event – it was listed in the Show catalogue, and a press release sent to the county newspaper. There was an item about the consultation on local radio with an interview from the event being broadcast live on the first day. The Public Involvement Officer for Suffolk’s health and social care services was involved in planning the Event, and made it known through her own channels.

The consultation took place in a prominent site at the showground, opposite one of the events rings, and next to the Disability Centre. Colourful banners and posters were designed to catch the eye and invite people into the Event, which was sited in an open-fronted marquee.

The total number of carers who participated in the event was 87. Carers were asked to give some personal details about themselves to build a profile of those participating, although not all chose to do so. Of those carers who gave their details, 39% came from rural areas. 54% of those who gave details of their age were under retirement age. Of these 34% were in full time or part time paid work.
The research for and publication of this report has been generously supported by Barclays. The bank recognises that carers support the very fabric of community and that their views should be included in both the local and national agenda. Over a third of Barclays community investment programme supports social inclusion and the bank aims to make a real and lasting difference.