Carers as Partners (CaPs) in social work education

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Carers as Partners (CaPs) in social work education

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# Forewords by the partners to this project

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Carers UK

Social workers have the potential to transform carers’ lives, to support and listen to them, and to give them the tools to have a life of their own alongside their caring role. Ensuring that from the start of their careers social workers understand who carers are, and what their needs are, is essential. Too often this does not happen and carers have to fight for recognition. Carers UK hears regularly from carers what a difference a good or bad experience with social services can make to their lives.

This research shows how higher education institutions (HEIs) are involving carers in training social workers, and the benefits this has for all parties, but also the challenges involved. We welcome the recommendations about spreading good practice in this area, as some institutions and local authorities are excellent at involving carers in some areas of their work. They must ensure that they involve a wide range of carers, reflecting the diversity of the carer population. After all, any of us could become a carer at any time. We know how we would expect to be treated and we would therefore encourage all institutions to take note of the findings of this thorough research.

Imelda Redmond
Chief Executive, Carers UK

Crossroads Care

It has been extremely positive to be part of the Carers as Partners (CaPs) initiative and we warmly welcome the report. Over our 35 years of providing breaks and support to carers we have had numerous opportunities to see the value of involving carers in the training of our own staff, and other social care professionals and seen too the significant impact on students as they link real lives to theory. The report highlights that there is still misunderstanding about the meaning of the word ‘carer’, which in turn illustrates the poor awareness of the huge contribution made by the millions of people who provide support to a relative or friend. While some progress is being made in differentiating ‘carer’ from ‘care worker’, there is still a long way to go. Ensuring newly qualified professionals start their working life with that understanding will be a major step forward. It is critical that carers receive recognition and are seen as expert partners in care and therefore we are very much in support of these findings and recommendations. We too will encourage our network of local schemes to support and collaborate with HEIs seeking to engage with carers.

Anne Roberts
Chief Executive, Crossroads Care
The Princess Royal Trust for Carers

Our vision is for everyone to recognise that the six million carers in the UK are vital to the UK’s health, well-being and economy. The findings of this project indicate that the meaningful involvement of carers in all aspects of the design and delivery of social work education is key to the development of a social care culture that recognises carers’ vital role. We’d like to see the good practice identified in this report developed and consistently applied to model and underpin a partnership approach to social care, led by carers and service users, which focuses on meeting the diverse needs and aspirations of individuals, families and communities. Our mission is to make a positive difference to the lives of carers. We support the recommendations of this report and will be pro-active in disseminating its findings through our partnership with a unique network of 144 carers’ centres, 85 young carers’ services and interactive websites.

Carole Cochrane
Chief Executive, The Princess Royal Trust for Carers

University of Sussex

We have been very pleased and honoured to work with our partners on this project. As social work educators and researchers, we are keen to contribute to the developing evidence base on good practice in professional education, and in particular to broadening knowledge about the value and impact of participation. This report makes a start on that task, bringing together the many experiences, reflections, challenges and achievements of those who share a commitment to ensuring that the views and perspectives of carers are embedded within students’ learning. We are very grateful to all who have contributed to the research, whether as sponsors, funders, partners, advisers, participants or reviewers, and we look forward to witnessing further future developments in this important aspect of education practice.

Suzy Braye, Professor of Social Work
Andy Cheng, Research Associate
Imogen Taylor, Professor of Social Work
Department of Social Work and Social Care, University of Sussex
Executive summary

Background

This is a report of a project carried out by the University of Sussex School of Social Work and Social Care, in partnership with The Princess Royal Trust for Carers, Crossroads Caring for Carers, and Carers UK, on behalf of the Social Care Institute for Excellence (SCIE). The project, known as Carers as Partners (CaPs) in social work education, formed part of Stage 2 of a national (England) project commissioned from SCIE by the Department of Health (DH) in 2005, to develop a strategy to support the participation of service users and carers in social work education. Stage 1 of the strategy produced two reports, *Common aims: A strategy to support service user involvement in social work education* (Branfield et al, 2007) and *User involvement in social work education* (Branfield, 2007). Stage 2 initially involved reshaping the work to include a focus on carers in social work education and the formation of a national forum. It also included the commission of this project.

Research team and steering group

The project was undertaken by the University of Sussex in its role as a registered provider of research to SCIE. The project was co-led by Professors Suzy Braye and Imogen Taylor and was project-managed by Associate Research Fellow Andy Cheng. Andy combines personal and professional experience as a carer.

A project steering group was established comprised of representatives from the following groups/organisations:

- carers
- university staff contributing to carers’ involvement in social work education
- The Princess Royal Trust for Carers
- Crossroads Care
- Carers UK
- SWAP (Higher Education Academy Subject Centre for Social Policy and Social Work)
- local carers centre (involved in development in primary and community care)
- strategic commissioning (for carers) at county authority level
- SCIE.

The purpose of the project steering group was:

- to give guidance on processes, contacts and other aspects of the project
- to give guidance on the environment in which the project is set
- to inform project management and project work on issues and perceptions current in represented agencies that were relevant to the successful delivery of the project
- to provide an 'ideas pool' to inform design and delivery of the project.
Definition of ‘carer’

The project steering group agreed to employ the following definition of ‘carer’ for the purposes of this study (modified from the definition used by the Welsh Assembly, see http://wales.gov.uk/topics/health/socialcare/carers/?lang=en):

Carers are people who support family members or friends who need care, help or support. Carers can be adults caring for other adults, parents caring for ill or disabled children under the age of 18, or young carers under 18 who care for another family member. There is not a typical carer. Carers may be of any age, culture or religion, and from a diverse range of backgrounds. Some carers do not see themselves as carers, but see themselves primarily as a parent, child, wife or husband, partner, friend or neighbour.

Methodology

The aims of this project were:

• to identify and report on the ways in which carers are involved in social work education at qualifying and post-qualifying levels
• to identify the challenges encountered
• to identify and promote the exchange of good practice
• to explore how participation could be widened to include seldom-heard carer groups
• to create a national forum for carers involved in social work education
• to consult on the need for a web-based networking facility.

The delivery of the project was divided into four phases:

• Setting up, which included
  – establishment of a project steering group
  – development of an analytical framework for the project enquiry
  – securing ethical approval from the University of Sussex.
• Mapping, which involved 34 interviews predominantly carried out over the telephone. Twenty-three of these were with social work programmes in England and 11 were with carers’ organisations working with them. In addition contact was made with black and minority ethnic organisations, but with only minimal success.
• Consulting and communicating, which involved three regional cluster groups (RCGs) carrying out focus group workshops in three regions in England. These brought together 58 participants in total, 39 of whom identified themselves as carers with the rest being comprised of staff from local social work programmes and related agencies. A fourth cluster group based on the project steering group was run and this discussed initial findings in the context of the participants’ own perspectives on the questions addressed
• Analysis and reporting, which involved drawing together the data gathered during the second and third phases and preparing a project report for SCIE.
Key findings

Who the carers are

The study revealed different understandings about what it is to be a carer, and about whether HEIs accepted carers as self-defined or as nominees from carers' organisations. This reflects the diversity of understanding in the literature and may reflect varying expectations about who will be the focus of engagement by social workers in practice.

The majority of HEIs were involving from 4 to 20 carers in their programmes. There was a broad range of people cared for by the carers, although no single HEI reported attaining a wholly comprehensive range of experience. There was a lower representation of carers of people with substance addiction, young carers and young adult carers.

What activities carers were involved in

Carers were involved in four broad groups of activities:

Recruitment and selection of students on to social work programmes

The majority of HEIs involved carers in interview design of interview procedures, for example in giving feedback on devices such as questions to be used in interview, contributing to workshops to generate scenarios to use in the interview process and developing a DVD to use as a starting point in interview discussions. Fifteen interviewees reported carer involvement in interviewing, on interview panels or on observation teams for group interview activities. Two reported carer involvement in reviewing written material generated by candidates.

The HEIs reported barriers to involvement including the difficulty of maintaining fair and equitable interview practice for all candidates when it was not always possible for carers to attend all sessions, and the logistical challenge of providing sufficient numbers of carers to participate in interviews with, in some cases, over 250 candidates, where interviews were taking place throughout the year.

Teaching and learning

Carers were involved in the design, delivery and review of teaching and learning across a range of modules. However, mostly they contributed to modules to do with awareness of, and working with, carers, communication and listening skills and preparation for practice.

Twenty-two interviewees reported some carer involvement in the design of modules including, for example, being consulted for suggestions for teaching programmes via an HEI-run focus group (invariably combined with service users) or via a focus group run with support from a local carers' organisation. Examples were also found of carers as representatives on a programme advisory group or equivalent body. Creative approaches to involvement included pairing carers with academic staff to
act as critical friends or ‘buddies’ for course development work, engaging carers in creative workshops to develop learning materials and working with carers to express lived experiences in the form of artistic activities such as poems and art.

The most common role for carers in the classroom was to present their personal stories as case studies in either lecture or seminar presentation, or in the form of reusable film or digital media, sometimes referred to in the literature as ‘testimony of their experience’. Variations on this approach included carers as consultants for student workshops, providing advice to small groups of students engaged in practical sessions; carers observing and giving feedback on students engaged in role-play scenarios; carers participating in conferences as presenters and workshop leads alongside students; and carers using creative methods for expressing and reporting on their lived experiences, for example the development of an art group drawn from carers in partnership with a local gallery, or engaging carers in a drama group to produce innovative learning materials.

Several HEIs were engaging carers in work to develop reusable learning objects, using film and script writing, including pre-recording carers’ presentations as video footage, or using other methods to capture carers’ narratives.

**Assessment of students**

Carers were involved in the assessment of students through participation in the design of the assessment tasks and involvement in the assessment process itself, generally as the task related to student understanding of carers’ issues and their subsequent practice with carers. There were also examples of carers contributing to assessment of students’ readiness for practice and observing student practice in the classroom and providing subsequent feedback.

Less than a third of interviewees reported carers’ involvement in the design of assessment tasks, criteria and processes. This included feedback for academic staff that could result in changes to assessment activities, for example where carers led development of a section of a module and assessed that component (30% of the grade). There was a higher incidence of use of carers in the delivery of assessment and the most common method was where carers observed student presentations and provided feedback, typically with a focus on student understanding of carers’ issues. Carers have become involved in grading student work, and this may include providing moderating feedback on the module rather than specific feedback on individual students’ work, thus reducing the number of carers required for the assessment task.

The barriers to carer involvement in assessment included the view of some HEIs that assessment had to be carried out by academic staff, a concern that carers who assess must identify themselves, which could challenge a view that carer identity should be confidential, and ensuring carer confidence and competence to assess students’ work.

**Carer involvement in programme management and beyond**

The majority of interviewees reported carer involvement in programme management, including as representatives to a programme advisory group or equivalent body.
that informed course evaluation. One example was found where the seat was not interchangeable with that for service users. There were attempts to engage carers in a more influential role, for example carers acting as 'buddies' to module leaders and carers invited to programme away-days. There were examples of carer involvement beyond programme level and, for example, in one HEI a carer (and a service user) were involved in the recruitment and selection of academic staff through being invited to provide feedback to the interview panel. Several HEIs reported engaging with carers in the development of research capacity, others in the development of skills and understanding of academic staff. Where social work shared a faculty with other health disciplines, there were examples where this gave rise to a more extensive involvement programme, often with greater facilities and resources.

Barriers to carer involvement in programme management included examples where academic staff questioned the extent to which the curriculum should be linked to carer (and service user) experience, and tension arising from different perspectives between carers (and service users) and staff programme boards. Even where involvement in leadership and management of programmes was established, power imbalances were still recognised, although it was noted that carer involvement coordinators in many cases exhibited a significant amount of influence over the nature and progress of programmes.

Enabling carer involvement

Rationale for involvement

A range of reasons was given by HEIs for the involvement of carers; the predominant reasons included recognition of the value to practice of learning from direct engagement with carer experience and valuing an approach which reflected the inclusive ethos of the programme.

Carers highlighted a strongly motivated desire to improve services as well as a desire to make a difference and achieve recognition as equal partners in care. The benefits to carers’ self-esteem were also recognised. In only one example was the offer of pay seen as a significant motivation for carers to become involved.

Recruitment and selection of carers, including those seldom heard

Good use is made of community contacts to recruit carers. Engaging support from carers’ organisations brought significant benefits: (a) helping to cover associated recruitment costs and (b) facilitating access to black and minority ethnic and other more seldom-heard communities. Almost all interviewees reported little success in engaging with young carers and young adult carers, citing barriers of confidentiality and safeguarding concerns as well as lack of capacity to carry out engagement work.

In most cases there was no specific selection policy; some HEIs enlist almost any carer who applies whereas others require specific training or skills. Some HEIs seek carers with the skills, experiences and capacity to work effectively in a teaching environment (or provide related training). Others prioritise an ‘authentic voice’.
Half the interviewees reported providing skills training to support carers to become involved. In addition, examples were given of where HEI staff intervened to keep the carer focused on experiences that were relevant to the subject being taught or to mitigate the effects of involving carers with a strong personal agenda that was deemed not compatible with the educational aims of the programme.

**Sustaining carers’ involvement**

There was a notable difference in attitudes regarding encouraging or avoiding new entrants to the group of carers involved with a programme. On the one hand, there was a view that the regular inclusion of new members would mean that carers avoid becoming too ‘polished’ and over-professionalised and remain fresh and powerful, and on the other hand, there was an emphasis on carers becoming more accomplished and developing their teaching skills through remaining regularly involved.

Written protocols and ethical guidelines for involvement activities were few. The scope of provision of carer orientation, training and support among the programmes was diverse, including stand-alone courses focusing on skills for training and public speaking and in one case carers enrolled on a Carers UK training course. Examples were found of training in interviewing skills, role-playing, assessing student work and contributing to meetings; also provided was training in skills in using the internet and guidance to carers about managing personal information appropriately.

The need for support for carers and for debriefing was recognised where carers were sharing personal experiences. In addition, the need for support with practicalities such as making sure carers knew when and where they were expected to attend, and how to submit claims forms. There was a common concern regarding the limits of resources available for involvement coordinators, and about the demands on academic staff time of supporting carer involvement. There was variability in practice in whether support was routinely offered or only on request, and whether it was face to face or by telephone or email. There were examples of carers being encouraged to support each other, for example through a ‘buddy’ system or membership of an HEI-sponsored support group. On occasion the support role had been carried out by a local carers’ centre.

**Leadership and management**

The majority of interviewees reported that control of the involvement programmes was sited with academic staff and/or involvement coordinators. Less than half of interviewees reported that carers (and service users) were instrumental in the leadership and management of involvement programmes; for the most part this was through committee decision making within a steering or consultation group comprising carers, service users and academic staff. Five HEIs reported appointment of a carer to lead involvement work. In addition, there were examples of proactive carers pushing participation forward through the channels open to them for leadership and management of projects.
There were different views about where involvement coordinators would best be based. On the one hand, a base in a carers’ centre allowed for better communication with the wider carers’ community and access to support services; and on the other, a base in the HEI enabled communication with academic staff.

**Payments to carers for their work**

A wide range of payment scales and rates for different activities was reported. In most HEIs where payments were made, they were on a par with rates offered to professional staff for comparable work activities. Carers reported significant difficulties in negotiating fees due to the repercussions for benefits, and HEI staff, while sympathetic to the difficulties relating to benefits claims, ultimately viewed this as the carers’ responsibility to resolve. One HEI, however, had purchased a series of consultation sessions for carers (and service users) to provide them with expert advice.

While all interviewees recognised the need to fund replacement carer costs, the HEIs were divided on how to address this concern and used a range of strategies, none of which are ideal.

Whereas General Social Care Council (GSCC) funds are used to support carer involvement activities, in addition HEIs were often also drawing significant sums from visiting lecturer budgets to help meet costs of carers’ (and service users’) involvement. Where carer involvement was shared across a range of HEI departments there was the opportunity to share costs.

**Working with carers and with service users together in the HEI**

The study revealed only loose consensus about what it is to be a carer. Interviewees often cited ‘no difference’ between service users and carers. Over half the interviewees for the study were working with a reference group that comprised a mix of carers and service users. However, examples were cited of carers and service users modifying or withholding comments because of the mixed group membership; and where attempts to involve carers and service users together had resulted in tension and in some cases overt conflict related to difference in perceptions, attitudes and beliefs. One strategy was to involve carers and service users separately. However, there were also examples of carers and service users working together in joint presentations to help students gain awareness of the realities of conflicts of interest between users and carers that social workers deal with regularly in practice.

**Future participation**

There was clear consensus about the value of taking participation forward in the future. Interest was expressed in building on the work of an existing regional group and sharing and widening knowledge about practice, and engaging in collaborative policy and strategy development work, building on collaborative networks already established by HEIs. However, there were concerns about the organisational capacity and funding resources available to support such initiatives.
Recommendations

Definitions of ‘carer’

Programmes should consider developing their own explicit definition of ‘carer’ that would be included in programme documentation, enabling judgements about carer involvement to be more easily made. The GSCC might have a role in monitoring such definitions.

Carer involvement across the range of social work education activities

If carer involvement is to be systematically embedded, it would seem appropriate that the GSCC monitors the balance of activity across the range of possible types of involvement (for example recruitment, teaching, assessment, management), and expects there to be an underpinning rationale for the patterns of involvement observed.

Further exploration and development of student recruitment and selection practices is required, in order to promote wider carer participation while maintaining fair and equitable interview practice for candidates.

Programmes should consider their rationale for carer involvement in teaching and in assessment of students, and examine how this might be further developed, including beyond those core areas identified in this report.

Programmes should monitor and review levels of carer engagement across the range of possible types of involvement, and develop strategies and action plans to strengthen and support involvement in aspects of social work education where it is not already taking place.

Programmes should recognise the need for different types of skill development related to the specific activities undertaken by carers (for example interviewing, teaching, assessing written work and/or practice portfolios), and provide access to the specialised types of training and support necessary.

Recruitment of carers and support for their involvement

Given the importance of equal opportunity concerns, programmes should consider developing a recruitment and selection policy that can be publicised to carers and carers’ groups. This should include further clarity on the different purposes of participation and the skills and experience sought from carers.

Programmes should consider how to extend the range of carers involved and in particular take action to secure the involvement of more seldom-heard groups, including young carers.

Programmes should consider the need for written protocols and ethical guidelines for involvement activities. Such guidelines might include the recognition of the potential
personal impact of involvement and the provision of support where necessary to address this.

**Carer involvement coordinators**

Programmes still needing to develop structures for the organisation of carer involvement will find it useful to draw on models found in this study. In particular, dedicated and ring-fenced staff time, whether academic or contracted from elsewhere within a carers’ network or organisation, is helpful in taking forward the involvement agenda.

Involvement coordinators should be supported by a contract that is based on a formal appointment procedure and job description.

**Resources to support carer involvement**

The stakeholders in social work education must give careful and considered attention to the need for secure and adequate resources to induct, support and sustain carer involvement, including resources to support the work of carers’ centres in encouraging and supporting carer involvement.

The costs of any replacement care required in order to facilitate carers’ involvement must be resourced.

Further high-level work is necessary to remove some of the barriers to participation that arise from welfare benefits rules. This needs to be undertaken at national, rather than local level. Equally, guidance for programmes about how negotiation within local benefits rules flexibilities can produce useful local agreements, and which reassure carers, would be a helpful intervention from the DH.

**Working with carers and service users together**

It is important for future practice for students to explore the different perceptions and perspectives that at times may present as sources of tension and/or conflicts of interest between carers and service users.

Managing such differences needs careful preparation with students, carers and service users, and support for those involved. Programmes might develop mechanisms and structures for developing and managing this work.

If the involvement coordinator role combines responsibility for carer and service user involvement, the issue of balance and recognition of similarities and differences between the two groups is important to monitor and maintain.

**Further research**

Research is required into the outcomes of carer participation in social work education, to include outcomes for students, the academic faculty and carers themselves. Particularly pertinent will be research into the impact on students’ practice.
Research is required into the design and development of forms of carer and user participation that explore differences and similarities in perception, attitude and beliefs.

Research is required into the potential for, and models of, partnerships between HEIs and national/local carer organisations, and their role in promoting and sustaining carer involvement in social work education.
1 Introduction

This is a report of a project carried out by the University of Sussex Department of Social Work and Social Care, in partnership with The Princess Royal Trust for Carers, Carers UK and Crossroads Care on behalf of the Social Care Institute for Excellence (SCIE).

The project formed part of Stage 2 of a national (England) project commissioned from SCIE by the Department of Health (DH) in 2005, to develop a strategy to support the participation of service users and carers in social work education. Stage 1 of the strategy produced two reports, the first by SCIE and Shaping Our Lives, Common aims: A strategy to support service user involvement in social work education (Branfield et al, 2007) and the second by Shaping Our Lives, User involvement in social work education (Branfield, 2007). Stage 2 initially involved reshaping the work to include a focus on carers in social work education and the formation of a national forum. It also included the commission of this project.

1.1 Project aims

The original project aims were:

• to identify and report on the ways in which carers are involved in social work education
• to identify the challenges encountered
• to identify and promote the exchange of good practice
• to explore how participation could be widened to include seldom-heard carer groups
• to create a national forum for carers involved in social work education
• to consult on the need for a web-based networking facility.

During the course of the project, SCIE committed to the development of a web-based tool to support service user and carer involvement in social work education. This project therefore assisted by consulting on the purposes, processes and content of such a tool.

1.2 Context

In 2008 the DH published Carers at the heart of 21st-century families and communities (HM Government, 2008), a revision of the carers strategy (DH, 1999). This stated:

Our vision is that by 2018, carers will be recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet the individual’s needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen. (HM Government, 2008, p 9)

Commenting on a mixed picture of progress since publication of the original strategy in 1999, the strategy recognises that carers have ‘called for closer working between the NHS, social services and themselves’ (p 48). Work already published by SCIE
has explored ways of further developing and also measuring the outcomes of carer participation in services.

In 2002 the General Social Care Council (GSCC) undertook responsibility for accrediting universities to grant degrees in social work, committing themselves to the DH (2001) aim to 'reflect the needs of service users and carers for a high-quality service' (p 4). GSCC accreditation required a commitment from universities to 'consult with service users and carers to make sure their needs and opinions are reflected in the design and development of courses' (GSCC, 2002, p 21). At post-qualifying (PQ) level, the PQ framework further states:

User and carer involvement is an integral part of the revised PQ framework and users of social care services and their carers will be able to participate in all aspects of PQ education and training. In this way the framework will also ensure that the needs and expectations of service users and carers are at the heart of post-qualifying education and training. (GSCC, 2005, p 4)

There is thus a robust set of requirements for the involvement of service users and carers in social work education at all levels, and progress has been carefully monitored (Levin, 2004; Wenman, 2005). This present project can be seen as a further step in the process of meeting the requirements by identifying good practice and supporting the further development of carer involvement. It builds on the reports produced by Stage 1 of the national project.

1.3 Research team

The project was undertaken by the University of Sussex in its role as a registered provider of research to SCIE. The project was co-led by Professors Suzy Braye and Imogen Taylor. Suzy Braye has led the Department of Social Work’s participation strategy, and has researched and published on the involvement of service users and carers in social work practice, education and research (Braye and Preston-Shoot, 2006); Imogen Taylor, herself a carer, has specialist knowledge in the field of professional pedagogy, and has led an earlier SCIE knowledge review, including a practice survey, of partnership with users and carers within social work education (Taylor et al, 2006).

The project was project-managed by Associate Research Fellow Andy Cheng. Andy, a former young carer and a current parent carer, has professional experience as a carers’ information and development worker for a London borough, in which he was responsible for developing a carers’ forum and lobbying group, outreach and information service. He also has substantial experience in media and web-based design, project and event management and information and policy research. Concurrent with the project, Andy has been providing one-to-one support to carers as an adult carers’ support worker employed by a Princess Royal Trust for Carers centre.

Members of the research team had involved students in previous knowledge reviews (Braye and Preston-Shoot, 2005; Taylor et al, 2006). On this occasion a decision was made to use the limited resources available to focus on carer organisers and carer educators.
1.4 Project steering group

At the outset, a project steering group was established to equip the project with advice and information and the wide range of expertise necessary for its legitimacy and success. The group comprised representatives from the following groups/organisations:

- carers
- university staff involved in carers’ involvement in social work education
- The Princess Royal Trust for Carers
- Crossroads Care
- Carers UK
- SWAP (Higher Education Academy Subject Centre for Social Policy and Social Work)
- local carers centre (involved in development in primary and community care)
- strategic commissioning (for carers) at county authority level
- SCIE.

The project steering group was formed to serve the following purposes (see Appendix 1):

- to give guidance on processes, contacts and other aspects of the project;
- to give guidance on the environment in which the project is set;
- to inform project management and project work on issues and perceptions current in represented agencies that were relevant to the successful delivery of the project;
- to provide an ‘ideas pool’ to inform design and delivery of the project.

The project steering group agreed for this project to be identified by the title Carers as Partners (in social work education), also referred to as the CaPs project.

Project steering group, 1 June 2009
2 What we did

2.1 Project overview

The delivery of the project was divided into four phases:

• Setting up, which included:
  – establishment of a project steering group
  – development of an analytical framework for the project enquiry
• Mapping, which involved a series of telephone interviews with a number of social work programmes in England and carers’ organisations working with them
• Consulting and communicating, which involved three regional cluster groups (RCGs) carrying out focus group workshops in three regions in England
• Analysis and reporting, which involved drawing together the data gathered during the second and third phases and preparing a project report for SCIE.

2.2 Definition of ‘carer’

The project steering group agreed to employ the following definition of ‘carer’ for the purposes of this study (modified from the definition used by the Welsh Assembly, see http://wales.gov.uk/topics/health/socialcare/carers/?lang=en):

Carers are people who support family members or friends who need care, help or support. Carers can be adults caring for other adults, parents caring for ill or disabled children under the age of 18, or young carers under 18 who care for another family member. There is not a typical carer. Carers may be of any age, culture or religion, and from a diverse range of backgrounds. Some carers do not see themselves as carers, but see themselves primarily as a parent, child, wife or husband, partner, friend or neighbour.

This definition was selected for its breadth and its inclusivity.

2.3 Scope of enquiry

This project explored carer involvement in pre-qualifying and post-qualified social work education delivered by higher education institutions (HEIs) in England, accredited by the GSCC to deliver approved programmes.

2.4 Ethical approval

This project was subject to full ethical scrutiny and received ethical clearance and approval from the University of Sussex. In particular:

• the project was intended to preserve the well-being of those involved as participants, and its outcomes were intended essentially to be of benefit to carers involved in social work education and students on the programmes with which they work
• participants, including staff on social work programmes and carers with whom they work, other carers who joined the project and other stakeholders, were given
clear information about the nature of the project and their informed consent was sought
• participants were free to withdraw their consent at any time, including consent for
  the use of any material or data they provided
• appropriate facilities were provided to promote the full involvement of
  participants, including translation, interpreting and facilities for advocates
• in all contacts with carers, all effort was made to respond appropriately to
  sensitive content, and workshop participants' comfort was secured through
  adjustments to workshop style and pace
• appropriate arrangements were made for participants to seek support with any
  personal issues arising as a result of their participation
• all data provided by participants were anonymised prior to publication or
  presentation, unless express consent had been secured for participants to be
  named
• confidentiality was limited only by the need to ensure protection of children or
  vulnerable adults, and participants were made aware of this at the onset of their
  involvement
• data were treated in accordance with the requirements of the Data Protection Act
  1998, and the requirements of other legislation (Human Rights Act 1998, Disability
  Discrimination Acts 1995 and 2005, Mental Capacity Act 2005), insofar as they
  relate to research, were observed.

2.5 Phase 1: Setting up

This initial stage involved making contacts with participants of, and convening, the
project reference steering group (see Section 1.4). Contacts were also made with
other stakeholders (such as Shaping Our Lives). Ethical approval was secured. In
addition, it was necessary to identify target participants for the mapping phase (see
below) and to pilot the telephone interview guide. Working from the project aims and
focus, and incorporating published requirements on carers' involvement, the project
team devised an analytical framework to facilitate the mapping, data gathering
and analysis of how carers may be involved in social work education and the likely
requirements for enabling involvement.

2.6 Phase 2: Mapping

This phase involved the purposive sampling of social work programmes in England,
using the analytical framework as the basis for a survey guide for telephone
interviews. The guide incorporated questions about the role of the interviewee
within social work education, the numbers of carers involved, the extent of their
involvement and the rationale employed for their inclusion. In addition, two
questions were designed to consult on the need for a web-based networking facility.

Two versions of the survey guide were developed, one for educational professionals
(Appendix 2) and one for carers (Appendix 3). These provided the basis for semi-
structured telephone interviews. The project employed a 'chain sampling' strategy
(Patton, 1990) beginning with an initial call for information (Appendix 4) distributed
via 11 forums on the national academic mailing list service, known as 'JISCmail',
selected for relevance to social work programmes and to carers. Table 2.1 shows the distribution.

**Table 2.1: JISCmail forums posted**

<table>
<thead>
<tr>
<th>Forum Name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>BOLTONFORUM</td>
<td>Bolton Forum in Health and Social Care</td>
</tr>
<tr>
<td>CARER-FORUM</td>
<td>Carer forum</td>
</tr>
<tr>
<td>CHILD-CARE-TEACHERS</td>
<td>Mailing list for childcare teachers in social work</td>
</tr>
<tr>
<td>E-LEARNINGINHEALTHANDSOCIALCARE</td>
<td>Developing e-learning in health and social care</td>
</tr>
<tr>
<td>JUC-SWEC</td>
<td>Joint University Council’s Social Work Education Committee</td>
</tr>
<tr>
<td>SCARE</td>
<td>Social Care Access to Research Evidence</td>
</tr>
<tr>
<td>SPIRITUALITY-SWED</td>
<td>Religion and spirituality in social work education</td>
</tr>
<tr>
<td>SOCIALWORK-ALCOHOL-DRUGS</td>
<td>List for social workers working with substance use issues</td>
</tr>
<tr>
<td>SOCIALWORK-ANTI-RACISM</td>
<td>Socialwork-anti-racism</td>
</tr>
<tr>
<td>SOCIALWORK-HEALTHINEQUALITIES</td>
<td>Contacts and members of Social Work and Health Inequalities Network</td>
</tr>
<tr>
<td>SOCIAL-WORK-SWAP</td>
<td>Social work</td>
</tr>
</tbody>
</table>

The project researcher also attended a Developers of User and Carer Involvement in Education (DUCIE) meeting and requested nominations for interview via this network. In addition the project researcher approached contacts nominated by the project team and by members of the project steering group.

This resulted in contact being made with 51 of the 81 GSCC-accredited HEIs providing social work programmes in England in 2008/09. From these contacts, 19 interviews with HEI staff took place (all those who agreed). To increase the sample, a random selection of nine of the remaining 30 HEIs was selected and an approach was made to the head of department for each. This resulted in a further four interviews with HEI staff. The HEI staff interviewed were those with responsibility for coordinating or facilitating carer (and often user) involvement in their programme. They included both academic staff and project workers, sometimes themselves carers, employed specifically to undertake the coordination role.

The project also contacted several organisations with a specific remit for working with black and minority ethnic groups:

- The National Black Carers and Carers Workers’ Network
- Black and Ethnic Minority Carers of Nottingham and Nottinghamshire (BECONN)
- The Afiya Trust
- Coventry Carers Centre: Milan Asian Group.
Only one of these contacts led to additional contacts being made. The research team was also referred to 18 further contacts, in part from conversation with earlier interviewees and in part from positive responses to suggestions from the steering group. This resulted in an additional 11 interviews with carers’ organisations.

In total the project carried out 34 interviews. Table 2.2 shows the mapping sample, and Table 2.3 the composition of roles carried out by the interviewees.

Table 2.2: Mapping sample/population comparison

<table>
<thead>
<tr>
<th>Role</th>
<th>Number interviewed</th>
<th>Number contacted</th>
<th>Total population</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HEIs</strong></td>
<td>23</td>
<td>60a</td>
<td>81</td>
<td>Running social work programmes; GSCC accredited</td>
</tr>
<tr>
<td><strong>External organisations</strong></td>
<td>11</td>
<td>18b</td>
<td>260+</td>
<td>144 carers’ centres associated with The Princess Royal Trust for Carers 110–120 centres associated with Crossroads Care Unspecified number associated with Carers UK</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>34</td>
<td>78</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes:
- a The projected inevitably contacted more than one member of staff for some HEIs as in some areas carer involvement was the responsibility of many people. The actual number of staff contacted was 84.
- b Only groups recommend by HEIs or the steering group members were contacted.

Table 2.3: Who we spoke to

<table>
<thead>
<tr>
<th>Role (job title or description)</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Programme leader or teaching staff/lecturer (any grade) with responsibility for carers’ involvement (three of whom additionally identified themselves as carers or former carers)</td>
<td>17</td>
</tr>
<tr>
<td>Carer (and service user) involvement coordinator/facilitator employed by the HEI</td>
<td>5</td>
</tr>
<tr>
<td>Carer/former carer participating (or wishing to participate) in social work education</td>
<td>4</td>
</tr>
<tr>
<td>Representative from a carers’ organisation</td>
<td>3</td>
</tr>
<tr>
<td>Carer (and service user) involvement coordinator/facilitator situated with an external organisation</td>
<td>2</td>
</tr>
<tr>
<td>HEI research staff</td>
<td>1</td>
</tr>
<tr>
<td>Local authority carers policy officer</td>
<td>1</td>
</tr>
</tbody>
</table>
2.7 Phase 3: Consulting and communicating: RCGs

Three RCGs were planned to enable issues to be explored in more depth than was felt to be possible in telephone interviews. The purpose of the events was to consult and facilitate communication on some of the matters that formed the main aims of the project – that is, a rich description of the ways in which carers’ participation takes place, the challenges associated with participation, the good practices established, the means of widening participation, the role and form of a national forum and the need for a web-based communication and networking facility.

A review of the responses from the mapping phase indicated that arranging cluster groups in the South West of England, Birmingham and Manchester would reach diverse groups of carers. This selection was made on the basis of geographic locations that, based on the mapping phase, had the greatest level of carer engagement in social work education activity and, in addition, indicated a positive interest in participating in a regional group.

A further consideration was to ensure that cluster groups were located in different Skills for Care (S4C) regions, and S4C representatives were invited to attend. The three regions selected were:

- South West of England
- West Midlands
- North West of England.

The project team, with support from the project steering group, devised a focus group programme to elicit rich detail about the experiences of RCG participants (Appendix 5). Three key questions were identified for exploration in the RCGs:

- What are the features of effective and successful involvement of carers in social work education?
- What are the features of effective ways of engaging seldom-heard or hard-to-reach carers and enabling them to get involved?
What are the best ways of accommodating work with carers alongside work with service users in social work education?

The RCGs also included two follow-on questions:

- What do you think the priorities are for carers in social work education?
- What (if anything) will you take away from today?

In addition, the RCGs included a question designed to consult on the content needed in a web-based networking facility.

The project team adopted an 'appreciative inquiry' (Ludema et al, 2000) approach to how the workshops were facilitated. This was to enable participants to go beyond the identification of problems and concerns and speculate on the possible solutions to these, informed by the details of any 'good' practice they had experienced. ‘Good’ practice was self-defined as it was not possible to evaluate outcomes within the scope of this project.

In order to ensure the sessions were as accessible as possible to carers, many of whom were expected to have limited time available away from cared-for persons, and to allow time for travel, the sessions were planned for a period of 3.5 hours, from 11.00am to 2.30pm.

The project contacted relevant interviewees from the mapping phase to invite them to participate in the RCGs. Members of the project steering group representing carer-led organisations provided substantial assistance in helping to engage local participation and recruit carers who were not otherwise involved in social work education to these events, acting as champions to relevant local carers’ organisations and projects.

In addition the project enlisted substantial help from the S4C South West region-funded regional advisory group for the South West, from the Centre for Excellence in Interdisciplinary Mental Health (CEIMH) for the West Midlands and from the Manchester Carers Centre for the North West.

It was agreed that each event would have a target minimum of eight carers plus key educators and representatives from other related agencies (provided the latter did not outnumber the carers). The actual numbers of participants are set out in Table 2.4.

**Table 2.4: Breakdown of participants at RCGs**

<table>
<thead>
<tr>
<th>Number of people attending</th>
<th>South West</th>
<th>West Midlands</th>
<th>North West</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delegates</td>
<td>5</td>
<td>19</td>
<td>21</td>
<td>45</td>
</tr>
<tr>
<td>Of whom, number of carers</td>
<td>4</td>
<td>12</td>
<td>15</td>
<td>31</td>
</tr>
<tr>
<td>CaPs and local support team members</td>
<td>3</td>
<td>4</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Of whom, number of carers</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>23</td>
<td>27</td>
<td>58</td>
</tr>
</tbody>
</table>
Members of the project steering group were invited to attend as co-facilitators at the RCG and three did so.

All participants were invited to complete a feedback questionnaire at the end of the event. The questionnaire included specific questions about whether participants thought this type of group should continue to meet beyond the project and what actions, if any, participants were thinking of doing as a result of the day.

At the suggestion of the project steering group, the project held an additional focus group based on the membership of the steering group. This took place after the completion of the RCGs. A snapshot of findings from the RCGs was made available to members to inform this discussion. Project steering group members who had attended some of the RCGs were able to provide informed comments. Steering group members discussed the same three key questions dealt with at the RCGs:

- What are the features of effective and successful involvement of carers in social work education?
- What are the features of effective ways of engaging seldom-heard or hard-to-reach carers and enabling them to get involved?
- What are the best ways of accommodating work with carers alongside work with service users in social work education?

2.8 Phase 4: Analysis and reporting

The data from the mapping and consulting phases (Phases 2 and 3) were collated and subjected to manual thematic analysis, using the analytical framework identified at the start of the project and designed to illuminate the key areas of focus within the project aims. To conduct the analysis, use was made of recordings made at the RCG events, notes taken by dedicated scribes at those events, and documents (such as small group flipchart feedback) produced on the days.
The project made two interim reports to SCIE specifically reporting on the data gathered in support of development of the web tool. The first report (January 2009) presented collated data regarding:

• current and past use of the internet to assist the development and delivery of involvement of carers in social work education
• extent of interest in the development of a web tool.

The second report (May 2009) presented RCG responses to the question: ‘What topics should be covered by the website?’ Both reports are incorporated within this final project report.

This present report is the final project report relating to all the activities described above.
3 What we found

3.1 Who the carers are

“When you ask a bunch of students, when they come in, what a carer is, they will almost certainly talk about care workers – that would be their main understanding of a carer. And it is not until you stop that and say you need to add a ‘worker’ to the end of it, that expression, that’s when they start to understand.” (external participant)

As this quote suggests, the study revealed different understandings about what it is to be a carer and therefore about who was ‘qualified’ to be involved as such in social work education. This reflects the diversity of understanding in the literature and may reflect varying expectations about who will be the focus of engagement by social workers in practice.

None of the 23 HEIs reported having a formal definition for ‘carer’, although 18 interviewees confirmed that they found the definition used in this study corresponded closely to their own understanding. But there were some significant exceptions or extensions to the definition, some respondents indicating:

- that carer workers are included
- that the carer’s role must at least correspond to the carers’ legislation requirement for a substantial role
- that foster carers are included
- that young carers are not included
- that no distinction is made between service users and carers.

Other refinements to the definition that emerged during the project included emphasis on:

- where the carer has responsibility for the quality of the service user’s life
- where the carer’s own life goes ‘on hold’ to some degree because of the role
- where the carer is providing intimate personal care.

Eight HEI interviewees reported that they engaged with carers who self-defined as carers, while five other HEIs reported that they accepted nominations from a local carers’ organisation, devolving responsibility for confirming the participant’s carer status to the carers’ centre.

1 Under the Carers and Disabled Children Act 2000, carers aged 16 or over who provide a regular and substantial amount of care for someone aged 18 or over have the right to an assessment of their needs as a carer (Direct.gov.uk 2009). There is no national definition of ‘regular and substantial’ in this context and while to qualify for carers’ allowance a carer must be providing over 35 hours of care each week, many local authorities accept receipt of Attendance Allowance or Disability Living Allowance by the person cared for as an indicator of a need for caring and therefore a carer role being fulfilled.
3.2 Number of carers involved

Of the HEIs engaged in the project, the majority were involving from 4 to 20 carers in their programmes. The average number of carers was 9, and the range that occurred with greatest frequency was 4 to 6. This was comparable to the findings of a recent study undertaken in the South West (Brown et al, 2008), which surveyed six HEIs and reported a range from 3 to 12 carers.

Twenty-six of the HEI interviewees reported that they engaged with a limited number of carers for key activities (such as actual involvement in teaching and other intensive activities). Over half of these reported working with a group of 12 carers or less. Figure 3.1 indicates the numbers of carers involved in the HEIs surveyed.

![Figure 3.1: Number of carers in key roles in HEIs surveyed](image)

Twelve HEI interviewees reported that they also referred to a much larger group of carers who had a significantly less intensive role in the social work programme. Of these, three HEIs reported that they engaged with local carers’ organisations to access the larger group. Interviewees reported that these groups ranged from 20 to 1,400 carers.

3.3 Who carers care for

There was a broad range of people cared for by the carers working with the programmes surveyed, although no single HEI reported attaining a wholly comprehensive range of experience. There was a lower representation of carers of substance addiction, young carers and young adult carers (aged 18 to 24). There was minimal representation of carers of cancer and acquired brain injury. PQ social work programmes reported a specific focus on carers in the fields of mental health and children and families, reflecting the more specialist nature of these programmes. Figure 3.2 reflects the range of caring experiences represented.
The issue of representation was contentious, as indicated by this interviewee:

“They can’t represent all other groups, who can? No one can! I mean I can’t represent all white women although I am one, because they are all so different – so I don’t think that is what we are trying to do. I think that we are trying to expand people’s thinking and understanding.” (HEI coordinator)

We return later to a discussion of the more seldom-heard carers.

3.4 Carer involvement in social work education

In this section we have grouped findings into the broad range of activities in which carers are involved:

• recruitment and selection of students to social work programmes
• teaching and learning
• assessment
• programme management.

We provide practice examples where available with the aim of illustrating the material made available during the project. The practice examples are descriptive; it was beyond the scope of this project to evaluate them.

3.4.1 Recruitment and selection of students to social work programmes

The study indicates that 15 of the qualifying degree programmes surveyed have made efforts to involve carers in the recruitment and selection of students. Two aspects of carer involvement were noted: the design of the interview processes and the delivery of interview activities. These emerged in both group and individual
Interviews. Figure 3.3 shows the spread of use of carers in the design and in the practice of interviews and indicates the number of external organisations (carers’ centres or external groups facilitating involvement work) that collaborated in this activity.

Figure 3.3: Involvement in interview group and individual design and practice

3.4.1.1 Involvement in interview design

Thirteen of the HEIs and one of the external organisations reported carer involvement in the design of interview activities. This included seeking formative feedback on devices such as questions to be used in interview. Three HEIs reported running workshops with stakeholders (including carers) to generate scenarios to use in the interview process. One of these reported working with carers and service users to develop a DVD to use as a starting point for interview discussions. One HEI reported requesting carers to propose questions for consideration in a paper for a written entrance exam. Another HEI invited carers to provide feedback to the admissions tutor after involvement in the process, in order to inform future development. Figure 3.4 shows the range of involvement in interview design.

3.4.1.2 Involvement in interview practice

Fifteen interviewees reported that carers had at least one seat on the interview panels and observation teams for group interview activities. Practice example 1 gives a typical example.

Practice example 1

“We’ve ... had carers and service users involved in the recruitment selection process. We’ve provided training for carers, service users and employers in the process and they then assist us on recruitment days where we have the students do a written exercise, and then we have group activities where they have group discussions around topical issues and certainly the carers and services users quite often will lead and facilitate those groups ... they feed back from those groups into deliberations on shortlisting for the selection process.”
Most reported that carers provided feedback in panel discussions and one HEI was explicit in stating adherence to the principle that the carers had an equal role in the activity. Two interviewees reported that carers were involved in reviewing written material generated by candidates.

There was some concern among interviewees about the difficulty of maintaining a fair and equitable interview practice for all candidates, especially in the context of incidents where carers were unable to fulfil their commitments to attend sessions, and thus some candidates were interviewed by carers while others were not. One overcame the concern by contracting with a local agency to fulfil the carers’ role in interviews, and to provide a replacement should a carer need to withdraw; another focused on establishing consistent standards for the interview process, regardless of who was conducting the interview. HEIs nevertheless reported significant logistical barriers to the involvement of carers, such as supporting sufficient numbers of carers to participate in interviews with, in some cases, over 250 candidates, sometimes taking place continuously throughout the year. Equally, problems arose for carers from changes of date and last minute cancellations necessitated by unpredictable attendance at interviews by candidates. Nevertheless there was a view that organising complete coverage was not crucial:

“How many people involved in interviews doesn’t really matter because there are standard questions and there is a kind of agreement about how the answers are scored.” (HEI coordinator)
3.4.2 Teaching and learning

3.4.2.1 Range of involvement

Carers are involved in the design, delivery and review of teaching and learning across a range of modules. Carer involvement most often appeared in modules to do with awareness of, and working with, carers, communication and listening skills and preparation for practice (14 interviewees cited these as examples). However, carers also contributed to the less obvious topics:

“I think there were some obvious places [where carers would participate] on the modules where you say, oh yes – human development, communication skills, assessment skills – some very, very obvious areas; but I think we are getting more and more creative and we’ve got tutors that sort of perhaps listen to us in one session and think ‘you’ve actually touched on something else – I never thought a carer could be involved in that as well.’” (HEI coordinator)

Carers were found to have contributed to the following areas of the curriculum:

- law
- policy development
- needs of multicultural communities
- specific conditions (eg mental illness, dementia)
- values and ethics
- user and carer assessment
- safeguarding children
- best interests assessment.

![Figure 3.5: Nature of carer involvement in interview practice](image-url)
In addition, three HEIs stated that they considered carers’ involvement relevant to all the modules taught.

### 3.4.2.2 Design of modules

Twenty-two interviewees reported some carer involvement in the design or evaluation of modules (18 HEIs and four external organisations). Ten of these were carers being consulted for suggestions for teaching programmes via an HEI-run focus group (invariably combined with service users) or via a focus group run with support from a local carers’ organisation. Figure 3.6 shows the range of ways in which carers were contributing to module design and evaluation.

**Figure 3.6: Nature of carers’ involvement in module design**

The majority of input provided by these consultations was utilised by academic staff with no further input from carers in the design of modules, although several HEIs reported that carers acted as representatives on a programme advisory group or equivalent body and had the opportunity to feed back on their observations of the teaching after delivery of the course modules.

A notable example where carers were involved more extensively in module development involved carers pairing up with academic staff to act as critical friends or ‘buddies’ for course development work, as shown in Practice example 2.

**Practice example 2**

“We started it in a small way last academic year with four members of the partnership initiative pairing with four tutors and those were to meet regularly to discuss areas of mutual interest, personal and professional development, both ways for each pair. In a couple of cases it led to the member of the partnership initiative planning with their buddy to come to a session in their module. Of the four, two were carers and a third was a mental health service user who is also a carer of her son. We are wanting to evaluate that, enlarge it and continue it for this academic year so around that we also put a bit of funding in a package that was agreed from Skills for Care.”
Three HEIs reported engaging carers in creative workshops to develop learning materials, working with carers to express lived experiences in the form of artistic activities such as poems and visual art, although at the time of this study they had no information about the effectiveness of these activities.

### 3.4.2.3 Delivery of teaching

Carers are involved in the delivery of teaching in a wide variety of ways, as shown in Figure 3.7.

#### Figure 3.7: Nature of carers’ involvement in teaching practice

The most common role for carers in the classroom is to present their personal stories as case studies in either a lecture or seminar presentation, or in the form of reusable film or digital media, as shown in Practice example 3.

**Practice example 3**

“They did something called ‘a day in the life’ where they had a PowerPoint, either on one of the slides, or spread over a number of slides. It listed the activities the carers undertook in a 24-hour period, which didn’t include a lot of sleep I have to say. And that has always been quite an effective part of their presentations to the students.”

This echoes discussion in the SCIE knowledge review of partnership work (Taylor et al, 2006), where Manthorpe (2000) referred to users and carers as ‘co-trainers’, or as ‘bearers of the testimony of their own experience’, with the emphasis on student understanding of user and carer experiences, recognition of their worth and expertise, and the reduction of discriminatory attitudes and stigma. Researchers such as North Americans Scheyett and Diehl (2004) describe the use of ‘structured dialogue’ where opportunities are created for students to hear from users and carers about their experiences. Scheyett and Diehl concluded that there is strong potential for the structured dialogue model to improve student attitudes towards, and learning about, people with mental illness, and to undermine the one-dimensional representations
and pre-existing stereotypes with which students may start out. Feedback from users and carers contributing to structured dialogue sessions indicated its validating and empowering potential for them.

The majority of examples in the present review were reported as carer presentations to groups of students which varied in size from small groups (of about four students), through seminars of up to 15 students, to large audiences of over a hundred students, where the carer has acted as a living subject for student scrutiny, often answering student questions afterwards. In three cases carers were supported to sit on a panel to facilitate engagement with large groups of students.

The study found four interesting divergences from this practice:

• Carers were employed as consultants for student workshops, providing advice to small groups of students engaged in practical sessions, for example devising a suitable intervention for a given scenario.
• Carers observed students engaged in role-play scenarios, or took part in role-plays with students. In one case the students carried out a role-play based on the story of a carer who was actually present, as in Practice example 4.

**Practice example 4**

“They decided to do something different; they decided to do a role-play of me and my mum's life. It was amazing to watch it and I thought this is really getting the message across.”

This is an interesting example because the carer was very positive about the value of this experience both for the students and for the carer. However, it would seem likely that some academic staff might be cautious about the risks of setting up such a role-play given the potential for the carer to be vulnerable to stereotyping or for the role-play to stir up difficult feelings.

• A conference format was used to provide an alternative teaching and learning environment. Carers were supported to participate in the conference as presenters, workshop leads and participants alongside students. Carers therefore attended with a different status to the one students had previously experienced them occupying:

  “It was a very good opportunity for students to engage in dialogue with carers and to go beyond the confines of a normal teaching session.” (HEI coordinator)

• Carers explored creative methods for expressing and reporting on their lived experiences. Creative examples using the arts are found in Practice example 5.
Several HEIs reported on work to develop reusable learning objects, engaging carers (and service users) in activities using film and script writing. Seven interviewees reported pre-recording carers’ presentations as video footage or onto other media, and several interviewees reported using other methods to capture carers’ narratives.

Clearly the involvement of carers in the direct delivery of teaching raises some challenges for others involved, although HEI academic staff generally welcomed these challenges:

“I have to admit I squirmed when some of the things were said about social work.... I would probably have put it slightly a nicer way, but it had to be done, and I just let that run because that was what they were there to do.” (HEI coordinator)

“Initial feedback from the students – I didn’t take it personally but they said that they’d much rather these guest speakers come in than listen to me drone on.” (HEI coordinator and lecturer)

### 3.4.3 Assessment of students

Assessment is a site of power in higher education and it is difficult for HEIs to let go of long-established processes. The study identified two ways in which carers were involved in the assessment of students: through participation in the design of the assessment tasks and through involvement in the assessment process itself.

#### 3.4.3.1 Assessment design

Less than a third of the interviewees (nine HEIs and two external organisations) reported carers’ involvement in the design of assessment tasks, criteria and processes. Carers’ (and service users’) consultation groups were asked to provide feedback for academic staff that could result in changes to assessment activities. Practice example 6 is an example of how carers’ feedback had affected the assessment specification.

A second example was where carers (and service users) were involved in reviewing student workbooks and participated in setting questions for the end-of-year assessment panel.
3.4.3.2 Carer involvement in assessment of student work

HEIs and external organisations reported a higher incidence of carers’ participation in the delivery of assessment (15 HEIs and 3 external organisations) than in design of assessment activities. Figure 3.8 shows the range of examples given.

Figure 3.8: Nature of carers’ involvement in assessment practice

![Figure 3.8: Nature of carers’ involvement in assessment practice](image)

The most common method for involving carers in assessment was to enlist carers to observe student presentations and provide feedback, specifically on the extent to which the student had demonstrated understanding of carers’ issues. Twelve interviewees cited this practice. There were also examples of extending this to other areas such as placement practice:

“We have tried to raise the profile of what used to be called ‘service user and carer feedback’, and we try to refer to it as carer and service user assessment so we...”

Practice example 6

“The students do an academic piece of work which is marked by the module leader and another, but they also have to do a plan of how they will involve people using services and carers in their practice placements and how they would involve them in the planning and the delivery of the service; and that piece of work is marked by the group; and that’s 30% of the grade. And in a way it is one of the hardest pieces of work, funnily enough. They can sit down and write an academic essay, but when you actually have to communicate clearly with people using services and carers, it’s about information – that’s sometimes where the social workers’ communication skills are lacking. And we say ‘well, you know nobody is going to read this, this language is too complicated, this is too long, this is not in a user-friendly form, what are you trying to tell people here?’ And actually the group are very good at actually identifying those issues and saying ‘this needs to be clearer, this is a really good thing; I know exactly what she is trying to say, I’d like to get involved in something like this’, on that level.”
regard that our service users and carers actually assess our candidates while they are in practice.” (HEI coordinator)

Carers have become involved in assigning grades to student work. One academic provided this example:

“The carer/service user was interested in the personal qualities and the substance of the knowledge base that the students demonstrated, that is, ‘would I like this person to be offering a service to me? Would I feel confident in that person?’... In the early days I took responsibility in determining grade but we are moving to a position where it is a collaborative, agreed grade.” (HEI coordinator)

An external organisation reported with some pride how carers’ input had recommended fail grades for students on a couple of occasions. These fail grades were confirmed and upheld by the associated HEI.

Involvement of carers in assessment appeared to be restricted to commentary on student understanding of carers’ issues and their subsequent practice with carers. For example, carers were involved in reviewing student practice portfolios or relevant sections of their portfolios, providing formative feedback with regards to the extent to which the students had demonstrated understanding of, and good practice regarding, carers’ issues. (Six HEIs and one external organisation reported this.) In some cases carers were enlisted to review a selection of portfolios in order to provide moderating feedback on the module rather than specific feedback on individual students. This was necessitated by insufficient resources to support carers and by insufficient capacity among carers to carry out extensive reviews, especially on courses which had large numbers of students enrolled.

We found two examples of where involvement extended beyond carers assessing knowledge or expertise about carers’ issues:

• Four HEIs and one external organisation reported that carers were also involved in the assessment of students regarding general readiness for practice, observing students alongside other stakeholders and academic staff.
• Two HEIs and one external organisation reported on carers either participating in or observing student practice skills in the classroom, providing feedback to the student.

There were also examples of carers participating in examination boards, although at times this would be experienced as tokenistic:

“We do occasionally attend [exam] boards but we don’t have any input, we are invited to attend to hear how things are decided and how the marks are allocated ..., in fact we go there because it is the polite thing to do to invite us because we are involved in other aspects.” (external organisation representative)

Some HEIs are reluctant to agree to carer participation in formal assessment as commented below:
“Involving carers and service users in formal assessment is a huge problem for us because the university doesn't like it. Formal assessment has to be carried out by academic staff as part of the academic framework. The only exception to that is something that is a professional body requirement such as practice assessment.” (HEI coordinator)

One HEI had overcome this barrier by ensuring that carers (and service users) involved in assessing students’ work were formally recruited and trained as associate tutors, and therefore held accountability as employees for their role in assessment.

A second barrier relates to confidentiality issues for the carer:

“We had a whole thing about confidentiality; previously any carer and service user feedback form was completely anonymous, but I took the view that if someone is assessing someone they don’t usually not put their name to it, so we went through a whole thing ... actually now service users and carers if they want to be identified can put their name to it. It is actually their work and their assessment of the candidate. If it’s anonymous it feels like it is on a lesser footing than another observer.” (HEI coordinator)

A third barrier is carer confidence and competence to assess students’ work. Interviewees expressed concerns about ensuring carers involved in the assessment process had the skills, understanding and capacity to do so effectively. An interviewee reported concerns about receiving carer feedback in time to inform the grading process.

Another expressed concerns about carer competence in a particular area:

“Carers said they don't feel qualified to mark how well students have been referencing their work.” (HEI coordinator)

One HEI reported seeking better clarity regarding the focus and function of carers’ involvement in assessment by supporting carers to carry out shadow assessment of students. Carers involved used the experience as a training exercise prior to their involvement in actual marking. We return in Section 3.6.2 to orientation, training and support issues.

3.4.4 Carer involvement in programme management

Twenty-one of the interviewees reported that carers were involved in programme management (16 HEIs and 5 external organisations). Of these, 10 HEIs and one external organisation reported involvement of carers as representatives to a programme advisory group or equivalent body. Twelve reported that a carer or service user was invited to programme boards as representatives of the HEI-maintained carers and service user consultation group. And eight interviewees reported the formation of standing consultation groups to inform course evaluation, in which carers participated as stakeholders. Figure 3.9 shows the range of ways in which participation in management was achieved.
Practice example 7 provides an example of where the carer’s voice appears to have had an effect on higher education (HE) practice.

**Practice example 7**

“We have a social work advisory group who meet roughly four or five times a year. They’ve been the principal advisory group over the development of the course, the validation process and all of that…. They have particularly stressed that we focus the students on their communication skills in terms of relationship building, because so much of social work over the last 10 years has tended to focus more on procedure, process and structure, and obviously the law. As some of the real benefits of social work tend to be those one-to-one intimate relationships that occur when you are engaging with the service user and carers, they have really wanted us to focus on students’ ability to engage with people and to see them as a person rather than the case.”

The study revealed some attempts to engage carers in a more influential role, with three interviewees reporting on carers acting as ‘buddies’ to module leaders, talking with them, shadowing and feeding back on programme management to the member of staff. Four HEIs reported organising specific stand-alone activities such as conferences and away-days to carry out course review actions, in which carers were invited to participate alongside academic staff and other stakeholders.

Two RCG participants confirmed their involvement in a review workshop. However, both lamented the fact that theirs had been very last minute invitations. An HEI reported holding dedicated joint carer/service user and staff meetings to carry out course reviews and to discuss new materials. Another HEI reported having a permanent seat for a carer on their management board. This HEI reported that the seat was not interchangeable with the seat for service users.

There was some conviction about the value of carer involvement:
“I think there is always a compromise, but I think it is important that you have involved in your planning processes people who will challenge you if they truly believe you are not getting it right.” (external organisation representative)

It is nevertheless difficult to know how much effect carer involvement has on programme boards and advisory groups. There were examples where carer involvement did not progress beyond consultation:

“There were no major changes from the discussion with service users and carers, but there were one or two refinements and one or two bits added around. We always wonder about asking about things like social work values, discrimination, etc around wording and so on that were quite useful.” (HEI coordinator)

There were reports of resistance by staff to carer involvement in programme management. For example, one HEI reported that academic staff questioned the extent to which the curriculum should be linked to carer (and service user) experience. And there were reports of some tension between carers (and service users) and staff in programme boards. One interviewee reported that some service users denied receiving any support from carers, a view not held by some of the carers involved at that HEI. This difference in view may reflect debates in the service user community about ‘caring’ as opposed to ‘personal assistants’ who are employed, an issue returned to in Section 3.7 where we examine some of the tensions and dilemmas as well as the gains of working with carers and users together.

The issue of the capacity of carers to be involved in social work education was also raised:

“Because what happens very often is that carers and service users are invited to those meetings (eg management) and often they make a very valuable contribution but the contribution is often constrained by their understanding of what’s going on, their understanding of the issues, the language that’s used.” (HEI coordinator)

This raises an important question of how much of the curriculum could be informed by reference to carers (and service users), and to what degree the management processes of an academic activity can be shared with other stakeholders. One interviewee discussed the difference of roles for carers in teaching and in programme management, citing that while there is a clear value for exploring personal stories in teaching and learning activities, the role of a carer in programme management should also include discussion of the underlying principles and values common to all carers and how they need to be reflected in the values and logistical practices of the programme. However, some carers may feel they are experts on their own experience but not necessarily experts about the experience of other carers in very different situations, or indeed on the learning experience of students.

Even where involvement in programme management was established, power imbalances were acknowledged:
“It’s very exciting because it can evolve into areas that we haven’t thought of, or perhaps the tutors hadn’t, because we can’t as carers go into the university and say we should be in that, that and that.... We can be part of an advisory committee and have suggestions but at the end of the day the module coordinators, the tutors, everybody putting the course together have got to find the time to look at it carefully....” (HEI coordinator)

Nonetheless, it was noted that carer (and service user) involvement coordinators in many cases exhibited a significant amount of influence over the nature and progress of programmes through their activities of selecting, briefing and in some cases training the carers (and service users) who got involved. Discussion at the RCGs indicated that several of the involvement coordinators were evidently unaware of the power and influence inherent in their roles.

3.4.5 Carer involvement beyond programme level

3.4.5.1 Carer involvement in the recruitment and selection of academic staff

Another context in which carers could potentially have a significant voice is in the recruitment and selection of academic staff. The project found one example that was in response to an initiative supporting inclusion instigated by the school's director. The carer (and other stakeholders) had the opportunity to meet the candidates for an academic post within a social work programme and provide feedback to the interview panel. However, members of this group had no direct representation on the interview panel itself.

Participants at the RCGs expressed interest in involvement in recruitment and selection of academic staff, but were unable to report on any initiatives working towards this.

3.4.5.2 Carer involvement beyond social work

Several HEIs surveyed incorporated health disciplines and social work within a single faculty or had developed strong links between these disciplines with regards to carer (and service user) involvement. Where this had occurred it appeared to give rise to a stronger involvement programme, often with greater facilities and resources; it also allowed programmes to be able to add value to the carers’ (and service users’) experience through being able to offer a wider range of activities and sectors that a participant could become engaged with.

From this emerged an interesting discussion about the extent to which the linking of carer involvement in education to the parallel practice of developing carer involvement in statutory sector governance may be beneficial. Involvement work in local statutory sector governance generally takes place through local involvement networks (LINks) and local strategic partnerships (LSPs) (and the subcommittees thereof), developing and monitoring local area agreements (LAAs) at county, city, unitary authority and borough and district echelons. This also applies on the micro level of the development of patient panels in general practitioner (GP) surgeries and GP cluster groups, which are emerging to provide a stakeholder-based governance
for practice-based commissioning. As a representative of an external organisation commented:

“...You don’t require high input to change people’s position on carers, it just needs to be explained ... well, and in a useful and easily understandable manner.”

There is significant work currently in progress with regard to the training of primary care practitioners, with sponsorship from a partnership of organisations including the Royal College of General Practitioners (RCGP), the Royal College of Nursing (RCN) and The Princess Royal Trust for Carers. The study was not told about any comparable initiatives with regards to carers and social work and social care agencies.

While it would seem that carers’ involvement coordinators, and in particular the carers themselves, have a potentially crucial role in brokering genuine power sharing in social work education as well as in the related fields of clinical and local authority governance, several interviewees and RCG participants reported the perception that service users were better represented at a lobbying level, both locally and nationally. Shaping Our Lives was often acknowledged as a particularly successful example of this.

While this study found many incidences of carers’ support organisations, the study found fewer indicators of carer representation with regards to lobbying for carers’ rights within the social work education industry.

Several RCG participants articulated a need for lobbying for carers’ rights in social work as a priority to emerge from this study. Two organisations surveyed their support of carers’ involvement in practice-based training and one participant called for actions to present the findings of this study to members of the standing commission for carers and appropriate government ministers via direct and person-centred meetings and events.

3.4.5.3 Carer involvement in research and training

While the study explored the development and implementation of carer involvement in many aspects of social work education, several HEIs reported engaging with carers in the development of research capacity, and a smaller number of HEIs reported carers’ participation in the development of skills and understanding of academic staff.

The study heard from two HEIs about how carers were engaged in staff training and raising departmental awareness and from several others about the use of carers in the research, analysis and reporting of findings in a range of publications. Three carers had published materials discussing their caring experiences. In one of these cases the carer reported that her book had been referenced in several primary care and specialist healthcare courses and she had been invited to present papers on the subject across the UK.

While the scope of this study has been carers’ involvement in degree (pre-qualifying) and PQ social work level education (as accredited by the GSCC) it is valuable to note the role carers have in other aspects of the HEI sector.
3.5 **Rationale: why carers are involved**

Practice relevance and direct engagement with experience was highlighted as a key rationale for involving carers.

“It’s about bridging the gap between theory and practice.” (RCG participant)

A strong sense of value, well established among staff at all levels, is a common feature of programmes in which a more fully developed practice of carer involvement was apparent:

“It’s that value-base richness of bringing the voice of people that are involved directly with the people that social workers work with.” (HEI coordinator)

“It’s something that we have been doing for some time and always found positive within the social work professional values, and these were values we want to put forward to students – to practice what we preach, in a sense.” (HEI coordinator)

While 10 of the HEIs surveyed specifically acknowledged that involvement of carers was a GSCC requirement, 11 HEIs stated that the practice of involving carers reflected the value base of the staff team and the programme. Many recognised service users and carers at the core of practice. One interviewee reported that there was strong support from the dean of their faculty and that as a result public involvement was reflected throughout the programme’s strategy. Five HEIs reported working with carers prior to the creation of the new degree in 2003. The range of emphases within the rationale for involvement is identified in Figure 3.10.

### Figure 3.10: HEI rationales for involvement of carers

One interviewee stated that the inclusion of carers gave a valuable different dimension to education practice, noting that carers were identifying, where some students where not always picking up, relevant concerns of carers in practice:

“Sometimes you have got to remember they [carers and service users] are not professional lecturers, their expertise is primarily of using services, or caring for people who use services and we have to keep that focus really. They are not there to do something that a lecturer could do, we are not asking them to draw upon
academic knowledge or academic references, we are talking about their own experiences and how that sheds light on the academic input.” (HEI coordinator)

Carers bring a specific experience to share, referred to in the literature as carers being the ‘bearers of the testimony of their own experience’ (Manthorpe, 2000), and echoed in the following quote:

“The advocacy group that we work with believes that the users’ and carers’ unique contribution isn’t towards academic practice, but their unique contribution is in terms of the more emotional, feeling side of practice. They say they don’t want to become academics, that is not what they are because they would just become like us, I guess. They want to have this distinct perspective.” (HEI coordinator)

Some HEI interviewees reported on discussions about a perception of a bias towards carers being seen as infallible and correct on all points. Among these there appeared to be a conclusion that the academic staff have a responsibility to represent accurately the wider range of carer-based expertise and the implications for a range of practice:

“Part of what we need to be able to have our social work students being able to do is to recognise that expertise and be able to engage with service users and with carers in such a way as to be able to negotiate an appropriate way of working with them.” (HEI coordinator)

Carers’ motivations to be involved are wide-ranging. Carers themselves, as reported by the representatives of external organisations interviewed for this study, highlighted a strongly motivated desire to improve services as well as indicating a desire to achieve recognition as equal partners in care. Eight of the 11 external organisations/carers surveyed reported that carers were motivated by a desire to improve the quality of services. Two of these specified a motivation borne from a concern about perceived failings in their experience of the services received. One interviewee reported that the carers who were involved were highly motivated by the perception that they were actually making a positive difference. Five external organisations/carers reported that carers became involved in education to gain value and recognition for the role of being a carer. In addition two interviewees recognised that carers they worked with benefited in terms of raising their personal esteem. One external organisation reported that carers become involved to fulfil social needs, acknowledging the isolation experienced by carers who have significant caring responsibilities. The range of reasons given is shown in Figure 3.11.

Only one external organisation reported that they thought the offer of pay was a motivation for carers to become involved but, as the following carer says, it was not a compelling factor:

“I like it [pay], but my loyalties, I have to say, would be where I am coming from and that is of a carer. My true loyalty is to improving services for people like my son and people caring for people like my son.” (HEI coordinator)
Issues relating to payment are returned to in Section 3.6.4.

### 3.6 Enabling processes

The study identified a number of processes that contributed to carers’ involvement in social work education.

#### 3.6.1 Recruitment and selection of carers

There were four key dimensions of recruitment and selection for involvement in social work education:

- how carers are contacted
- what criteria are used to select them
- how carers from seldom-heard communities are recruited
- how long carers are involved in social work programmes.

#### 3.6.1.1 Contacting, recruiting and retaining carers

The present study found that good use is made of community contacts at the beginning of carer involvement activities; however, there appears to be a notable drop off of such contact thereafter, with HEIs in the main preferring to incorporate engaged carers into their own communication and programme delivery processes, rather than continuing to work through community contacts. This impacts on the ability of social work programmes to feed back to the wider community on the involvement of carers in social work education, and to keep communication and recruitment channels open. In addition HEIs face a choice between developing parallel capacity to meet their duty of care responsibilities for the pastoral needs of the carers involved, or sidestepping this concern at the risk of disaffecting and disadvantaging the carers involved, and potentially reducing HEIs’ ability to replace carers as they move on.

One HEI reported that some of the carers were recruited via direct contact with local authority agencies such as social work teams. Five HEIs reported only using carers
personally known to staff and, of these, four reported that they were working with carers who had been involved with the course since the start of the degree. One HEI reported that carers’ involvement practice was met by using existing teaching staff who were also carers.

Fifteen interviewees reported that recruitment, at least initially, was carried out with the support of a local organisation such as a carers’ centre. Ten reported use of a series of special events often run jointly by a local organisation and the HEI that had the explicit aim of recruiting carers into involvement work. In addition five HEIs reported maintaining a development worker with a responsibility to network with external organisations to recruit new carers for HEI involvement. The range of recruitment strategies used is shown in Figure 3.12.

**Figure 3.12: How carers were recruited**

Engaging support from carers’ organisations brought significant benefits; for example one external organisation reported carrying out substantial work in accessing black and minority ethnic communities on behalf of their local HEI, building on their existing network of contacts. Other external organisations reported undertaking extensive work to help recruit carers, including covering associated costs such as event catering and meeting resources from their own budgets.

There were some difficulties identified in the initial stages of recruitment, in part as a result of the approach taken by HEIs:

“We had a very positive turn out, a good number of people who wanted to come. This again was facilitated by the carers’ centre, we even provided lunch at our own cost and at the end of it the lecturer said ‘give us your contact details and we will be in touch’. In our opinion the downfall then was the actual carers’ centre was taken out of the loop. There was no follow up, there was no additional support for the carers; and then the carers were contacting us and saying ‘we haven’t heard anything back. What are we suppose to be doing?’. We weren’t able to support these carers any further. As far as I am aware, out of all those individuals none took the training packages.” (external organisation representative)
Much work had been done to build trust and relationships between HEIs and external organisations, and it was trust that made a difference to how collaboration could develop:

“In the early days they [external organisations/employers] were very suspicious of us … there were two themes there I think really; one was about wanting to be assured of our motivation and integrity; were we just doing it because we'd been told to or did we have an intrinsic interest? And the second thing, which is what got us going, was about sharing a shared value base. And we spent quite a lot of time in workshops looking at that…. And once there was some trust over a shared value base – that is, it wasn’t about exploitation, it wasn’t about using somebody and dumping them, that there was going to be reasonable payment and those sorts of thing – then the trust that was necessary to work together effectively began to emerge.” (HEI coordinator/academic staff)

A key factor in the success of partnerships between the HEIs and external organisations was reported to be relationships at the level of individual practitioners:

“Very often it’s to do with the worker that we make a link with and their interest and response to us. That is how we first had quite a bit of contact with a carers’ centre. More recently with another carers’ centre, again the support worker herself said she could come to partner initiative meetings. She got to know us and the aims of the partnership initiative and so on. And now she has been most proactive and cooperative partner for recruitment, and so on.” (HEI coordinator/academic staff)

There were varying views among HEIs regarding the kinds of carers to be recruited. Some HEIs specifically, or by default, select carers for skills, experiences and capacity to work effectively in a teaching environment (or provide training to enable them to do so). Others seek to maintain an authentic voice as represented by untutored carers, with the HEI seeking a regular entry of new participants in order to prevent the cases and the potency of the presentations of those cases becoming diluted by repetition.

### 3.6.1.2 Selection criteria for carers

Most interviewees cited no specific selection policy or criteria; however, most supported carers to self-select based on an informal presentation about the work on offer. Two HEIs reported referring to written guidance and policies, neither of which specified the capabilities and capacity expected of a carer. One HEI cited an informal policy that no carer would be turned away.

Possibly as a consequence of the difference in views about the role of carers in social work education, there were different views about the criteria for selection and indeed whether there was any selection at all. Several interviewees stated that carers had to have appropriate training or skills to become involved. Two interviewees reported that they actively assessed carers on their ability to contribute to and cope with the expected work prior to engaging them. Two HEIs reported that they were only
recruiting carers where they had specific awareness, experience and skills to offer and that some carers would not be approached, for example:

“We didn't invite service users or carers who we thought would be out of their depth, because that is pointless. I only invited people who I thought had that cognitive ability, if you like.” (HEI coordinator/academic staff)

It is not clear what 'cognitive ability' refers to here and whether that meant that certain carers might not be selected after they had originally been approached, but it does indicate an initial screening by the HEI prior to invitation. The argument was given that some selectivity was needed to match carers to need:

“It’s not cherry picking, but we need to have a wide variety of people and need to know how to allocate them to the appropriate place.” (RCG participant)

Carers may also select the area of work they prefer to be involved with and to identify their anticipated limitations, at least initially:

“It seems most people gravitate to what they want to be doing. And if you say to somebody 'do you want to do interviewing?'. Quite a lot of people say 'No, I wouldn't want to be responsible for making the wrong choice'.” (HEI coordinator/academic staff)

Involvement coordinators reported paying specific attention to the areas of interest and preferences of the carers (and service users) and respecting these in placing carers within teaching sessions. One example of an open approach to selection is clearly described in Practice example 8.

### Practice example 8

“When someone approaches me and asks to take part ... I meet them in person ... and then I ask them to fill out a form, give me about a half page of who they are, a little about their caring role, whatever they want to tell me, something that they would be comfortable about me showing to the tutors. As well, because I think this is absolutely key to people's interest, is to say 'have you got two or three things that you are really very passionate about, something that you feel you would really like the social workers to know about because you have a passion about it' ... I circulate that as well and that's my way of getting away from 'that's what she is and would therefore only want to talk about that'.”

Half of the interviewees (17) reported providing skills training to support carers to become involved. Three HEIs reported specific instances where it emerged that the carers lacked skills and understanding about learning outcomes to the point where they felt they had to intervene, for example by chairing the discussion to keep the carer focused on experiences that were relevant to the subject being taught.
3.6.1.3 Recruiting seldom-heard carers

Early research into carers in the 1980s and 1990s explored how some carers do not define themselves as ‘carers’ and therefore initiatives designed to reach out to them are not successful. As such, some groups of carers may be seldom heard in social work education:

“There’s a large body of hard-to-reach carers who are self-funding, managing on their own, not turning to public services at all, who then don’t realise there’s a range of support available to them. I know, I’ve got some in my own family and they know what my job is, but they wouldn’t touch services, voluntary or statutory." (RCG participant)

Discussion with participants in the mapping and consultation phases of the project revealed the following groups of seldom-heard carers within the context of social work education:

• people with substantial caring responsibilities resulting from the disability, illness or frailty of the cared-for person who have not yet recognised or applied to themselves the designation ‘carer’
• carers unavailable during traditional consultation times, such as working carers and carers attending education institutions
• carers unable to leave their homes (due to the nature of their caring role or difficulties regarding travel such as the distances involved in rural communities)
• carers of people who are self-funding as regards services, with subsequently little or no contact with statutory service arrangements
• carers in excluded communities based on cultural distinctions, such as:
  – minority ethnic status (in particular, first generation immigrants)
  – sexual preference
  – religious orientation
• carers with no static geographic base, such as travellers and other nomadic groups
• carers with reduced communication or mental capacity.

Furthermore, caring work can be very onerous and carers may not want to focus on their caring role in the classroom:

“Carers are busy people and we find it’s difficult sometimes to engage with them, because of the fact that they generally have houses to run and if they’re getting a service provided to look after the person they care for then that time is precious and they don’t want to spend it sitting … talking to somebody about how blinking awful this is or how great that is…. It’s about how we would be pulling in the right people without adding to the pressure, so that it doesn’t become a pressure thing but something they are doing because they know that their experiences can improve things for the future.” (HEI coordinator)

We discovered that some programmes had successfully established links with black and minority ethnic communities, while others reported that they were struggling to do so. Invariably those HEIs with higher black and minority ethnic representation reported strong links with carers’ centres with black and minority ethnic workers.
One interviewee reported a tendency among certain communities to fail to recognise members with caring responsibilities as ‘carers’. Traveller groups and some black and minority ethnic communities were cited as examples of seldom-heard carers where local organisations may play a role in enabling recruitment:

“It’s interesting because a lot of hard-to-reach groups don’t seem to want to be involved with statutory agencies; thinking about travellers now, some BME [black and minority ethnic] groups who are in fact denying that they are carers in the first place. Those that want to get involved tend to be a certain type of person so I think there will always be a difficulty trying to reach those groups, but we tend to use our carers’ centre to do that because they are not seen as ‘statutory’; they are seen as this organisation that is saying ‘yes’ when everywhere else is saying ‘no’; they have a lot of respect from the carers they support.... We do tend to find it is sometimes those who are less able to express their needs who need support to do just that; to find their way through the maze.” (external organisation representative)

As the above person was suggesting, recruiting seldom-heard carers requires proactive approaches:

“There had to be this proactive approach and outreach to the BME communities which tended not to happen with the mainstream services but the voluntary organisations, especially the black voluntary organisations, tended to go where the communities were and set up stalls for information days and things like that. And if they didn’t do that, then contact just didn’t happen.” (HEI coordinator/academic staff)

Language and availability of interpreters may also be an issue:

“Language is a big thing and mainstream services didn’t use interpreters, they tended to use family members. The voluntary agencies were much better at recognising the need for same-language speakers and tried as far as possible to get staff who were representative of the communities.” (external organisation representative)

Almost all interviewees and participants at the RCGs reported little success in engaging with young carers and young adult carers directly. Several cited confidentiality and safeguarding concerns as a significant barrier for engaging with children and acknowledged there was little capacity to carry out engagement work at the times when younger people were available. Several reported attempts to engage with younger carers via postal consultations and via young carers’ projects to generate reusable e-learning objects (DVD and video), but we found no examples of notable success. This echoes findings from another recent study (Taylor et al, 2008) of the HE response to the integrated children’s services agenda which found minimal involvement of children and young people in HE teaching, except where this was supported by an organisation such as Barnardo’s.

Most interviewees cited limited resources as the primary barrier to successfully widening the diversity of carers involved. This was echoed with some emphasis in the
RCGs. For example, one group reported a cut back in S4C funding, resulting in it no longer being possible to fund carers to come together from across a widespread rural area.

3.6.1.4 Maintaining carers’ involvement

There was a notable difference in attitudes regarding encouraging or avoiding new entrants to the group of carers involved with a programme. There was, on the one hand, a strong emphasis on the advantages of a stable group of carers becoming more accomplished and developing their teaching skills through remaining regularly involved.

“As people [carers] get more knowledgeable on how to articulate something across, they become better with their words.” (HEI coordinator/academic staff)

“They come to appreciate who they are talking to; the students become somebody they really are trying to inform and as they get more confident and they realise the students’ questions are going to be very considerate and very supportive, they feel more able to say more and I think that they go into the classroom feeling more trusting of the situation. It is not like standing in a classroom and talking about a book of theory, this is like standing in the classroom and the book isn’t on theory, it’s your life. And the experiences are very personal to you and how somebody interprets your experiences is incredibly personal to you….” (HEI coordinator/academic staff)

There was, however, a concern for the impact on carers of participating in ways that drew on personal experience:

“One of the problems for me of a service user or carer being used directly in teaching all the time is that they can become burnt out. How many times can we expect people to share the pain and distresses of their stories without feeling that you’re starting to abuse them.” (HEI coordinator/academic staff)

Despite the value placed on carers becoming more skilled and confident with practice in the teaching role, five HEIs, on the other hand, reported a concern that they were experiencing an insufficient inclusion of new carers, noting that the carers involved were becoming too polished in their presentations of issues, resulting in an apparent loss of impact on the learning:

“We had a carer who talked to some students who was no longer actually caring for someone and one of the students said to me afterwards ‘well they’re not a proper carer, they talked about their experience doing that but it’s not real, it’s not what they are doing’. And it is almost like ‘we want to witness their pain now, they need to be experiencing that now’…. People want that raw element…. ” (HEI coordinator/academic staff)

One interviewee felt that the carers were becoming too ‘cosy’ with the programme. And another reported that they monitored carers to avoid the carer becoming ‘over-professional’ and adapting their point of view to be in greater synchrony with
the academic concerns. Despite the challenge, however, of avoiding a perceived over-cosy or over-professional relationship, there are clear benefits to be brought by experienced and skilled carers who may be embedded in the organisation to the extent that they have a clear understanding of and engagement with student learning:

“So the involvement is almost making sure they are embedded and that they can take part and can understand the key issues of a particular project.” (HEI coordinator)

3.6.2 Orientation, training and support

There was recognition of the need for induction and mentoring into carer involvement activities in the HEIs:

“The development of the active participation of ... carers actually requires a fair amount of resource as everybody knows and people don't just come on board and hit the ground and run, they need a lot of care and nurture and development.” (HEI coordinator/academic staff)

The study focused on two aspects of orientation, training and support: specifically, the support of carers to develop skills and capabilities to carry out their roles in the social work programmes; and the support of carers to sustain their involvement. The scope of provision of carer orientation, training and support among the programmes surveyed was fairly diverse, as was the depth to which interviewees perceived that their roles and responsibilities extended.

The extent of training and support was influenced by the level and volume of carer involvement. Where social work programmes had a greater number of carers (that is, over eight) they typically had a carer and service user consultation or advisory group in place, to maintain communication and foster a sense of engagement and ownership, supported by processes such as those described in Practice example 9.

3.6.2.1 Developing carers’ skills and capacity

Sixteen interviewees reported providing training and inductions to enable carers to get involved. Six reported using stand-alone courses focusing on skills for training and public speaking. In one case the HEI enrolled carers on the Carers UK ‘Equal partners training for carers’ course. One HEI reported that they were considering utilising
other external training such as that supplied by the local primary care trust. Four interviewees reported providing training for specific skills including:

- role-playing
- interviewing
- meetings
- recruitment and selection

Two HEIs reported providing training on request, including skills for using the internet. One HEI described providing guidance to carers to ensure that they avoided disclosing excessive and inappropriate amount of personal information. One HEI reported that they were engaged in developing a handbook for new participants; another had developed training in assessment, as seen in Practice example 10.

Figure 3.13 shows the range of provision made for developing carers’ skills and capacity.

**Practice example 10**

One HEI reported seeking better clarity regarding the focus and function of carers’ involvement in assessment by supporting carers to carry out a shadowing assessment of students, shadowing an academic assessor. Carers involved used the experience as a training exercise prior to their involvement in actual marking.

A study carried out by Bournemouth University (Brown et al, 2008) found similar use of training among the six HEIs that were surveyed, with training provided at yearly sessions at one HEI, and specific training offered (for example, confidence building) at another. Use of trainers from outside the HEIs themselves was also referred to.

Training may be a route to helping carers become aware of what is not appropriate; two interviewees expressed concerns about experiences with carers who attended
involvement sessions with strong personal agendas which they felt were not compatible with the educational aims of the programme. One HEI reported that some academic staff had expressed frustration at the lack of educational professionalism among some carers (and service users):

“Portfolio reading is a specialist skill and you have to have people that know the background of it and you know this comes into the training.” (HEI coordinator/academic staff)

Without exception, with regard to the issue of capability to participate in education activities, HEIs made no distinction between carers and service users, although one HEI reported academic staff had to take on personal assistant activities for a service user who attended with no additional care worker support. This information was greeted with some incredulity by other members of the RCG and seen as very inappropriate for all concerned.

3.6.2.2 Supporting carers

The need for support for carers was widely acknowledged:

“People are talking about intimate and very personal things and it needs proper follow up, proper debriefing, feedback; how was it for you? how do you think it went, how did you feel? – not just leaving people and saying thank you very much that was really interesting and bye, bye. Because I think there is a lot to the success of groups … and that takes time, and it takes money and it take involvement. And I think that’s what puts people off some times – because it is a huge commitment if you are going to do it properly.” (HEI coordinator)

Carers’ anxieties about the practicalities of their involvement were also recognised:

“… the level of anxiety that the carers and services users have over the practicalities of their involvement tends to outweigh the anxiety over what they are able to achieve. They feel very confident that what they are saying and what they are bringing is valuable and important. What they tend to be anxious about is having a recognised contact so if there’s a change in the lecture room that they are going to that they know they can get to the relevant one. Things like that. Making sure that taxis are booked, making sure that claims are processed appropriately, making sure that grants are accessed and facilitated well. We tend to have to go through a lot of orientation about those sorts of processes.” (HEI coordinator)

Eleven interviewees reported that the social work programme’s involvement coordinator had responsibility for providing supervision and practical support. Seven interviewees reported offering debriefing sessions, although sometimes only on request. One HEI reported offering a debriefing service via email or telephone only.

Figure 3.14 shows the range of ways in which carers are supported in the context of their work with the HEIs.
In addition to debriefing, involvement coordinators provided a varied range of support, including:

- mentoring the conversion of a personal story into a presentation
- semi-formal meetings with a social element
- assistance in finding funding for support workers for carers
- advocacy (for external concerns)
- benefits and payment advice.

Figure 3.15 shows the range of support provided by involvement coordinators.
Eleven interviewees reported that carers were encouraged to support each other, eight of these via a ‘buddy’ system and six (with some doubling up) through membership of an HEI-sponsored support group. Six HEIs reported that any supervision and practical support was delegated to the member of academic staff with the lead role for a given module.

On occasion the support role had been carried out by a local carers’ centre. This was seen as potentially highly effective if the carers’ centre was familiar with the programme:

“One of the advantages of working through the local carers’ centre was that the development workers there were able to offer support to individual carers. They had preparation sessions there so we relied very much on our colleagues in there to support carers.” (HEI coordinator/academic staff)

One HEI reported that it had contracted support services from a local carers’ centre; however, as the carers involved were now embedded in the programme the support was no longer required.

Eight interviewees reported concerns regarding a shortage of resources to carry out effective support. Six reported lack of staff time and two reported a shortage of suitable provision.

3.6.3 Leadership and management

We examined the leadership and management of carers’ involvement in programmes and, in particular, the role of carers in those processes.

The study interviewed 17 academic staff with responsibility for carers’ involvement, five non-academic staff hired by HEIs for this lead role and two external organisations that were contracted to provide this role. The majority of interviewees reported that control of the involvement programmes was sited with staff and/or involvement coordinators. Of these, 12 interviewees sited this responsibility with a development worker (involvement coordinator), and three stated that involvement work was led by academic staff.

Less than half indicated that carers (and service users) were instrumental in the leadership and management of involvement programmes; for the most part (10 cases) this was through committee decision making within a steering or consultation group comprising carers, service users and academic staff. Five of the HEIs surveyed reported having a carer leading the involvement work, two as HEI-employed non-academic staff and three academic staff who acknowledged their identity as carers. One interviewee identified himself as a member of the academic staff at one HEI, but with responsibility for carers’ involvement across several HEIs in the region. Another interviewee, reporting from within an HEI with a very established involvement programme, described monthly meetings of a steering group that had regular involvement from the assistant dean who was taking a lead in this initiative.
Carers were also proactive in pushing participation forward through the channels open to them for leadership and management of projects, as demonstrated in Practice example 11.

**Practice example 11**

“They are extremely pro-active in what they want to get involved in and they have now gained a lot in confidence; so they tell me what they want. In fact, there was a particular module ‘Preparation for practice’ which they felt they should have more involvement in and they’ve asked me to contact the module leader so they can talk to her at their next meeting about how they can be further involved in that module because they have all sorts of ideas of things they would like to do there. So they are actually taking the lead in many ways on a lot of the activities that they are doing.”

Other carers, however, reported having restricted access to academic staff and only ‘arm’s-length’ input into management of the involvement programme.

Two HEIs reported having produced written protocols and ethical guidelines for involvement activities, both produced with reference to their respective consultation groups. These activities reflect a process of refining experience, for example in relation to the important issue of managing the ethics of involvement, as discussed in Practice example 12.

**Practice example 12**

“We’ve designed confidentiality statements and all sorts of things, but it is quite difficult to ensure that if you are a young person giving a presentation and you suddenly recognise somebody in the student group who you have worked with in the past – to know how that’s handled. And similarly with carers who may have been involved with either our students in a different life or ... we had a lady with a learning disability who suddenly came face-to-face with her key worker. So we have to build in some sort of protection around those issues. We don’t think we have got it quite right yet.”

There was recognition of the importance of dedicating time to leadership and management of involvement, particularly as participation becomes more complex and extensive:

“... it’s moving on from the expectation of the [personal] story bit to incorporate that in the range of activities carers can do. How does that move? I would say it needs, it takes a paid worker in order to be able to negotiate between carers and training staff, in order for that to happen.” (RCG participant)
There seemed to be significant benefits gained through the employment of an involvement coordinator to deliver all the aspects of work associated with successful involvement of carers. There were differences of opinion on where involvement coordinators should be based. There is an argument for carers’ involvement coordinators to be sited, in part, in carers’ centres to allow better communication with the wider carers’ community, to provide seamless access to support services to assist carers in engaging with HEIs, dealing with any repercussions both practical and emotional, from such engagement, and to enable HEIs to access a pool of carers to support management of the natural turnover of participants.

There are, nevertheless, clear benefits arising from carers’ involvement coordinators being sited in HEIs, enabling easy communication with academic staff, module leaders and programme management:

“... the key for any user and carer group is they need to be based at the university, because if you are based there, you, if you have shared offices, you are then embedded with the lecturers, they can starting seeing you. Some of the issues you need to address are how lecturers deal with carers and service users.” (HEI coordinator)

3.6.4 Resources

The study identified three key aspects relating to the resources needed to facilitate the involvement of carers:

• making payments to carers for their work;
• covering the costs of access and support for carers;
• meeting the ongoing resource requirements for development and maintenance of involvement work.

3.6.4.1 Making payments to carers for their work

Interviewees and participants at the RCGs reported a wide range of HEI payment rates for carers, and these in turn varied within HEIs, according to the type of activity being carried out by the carer. This ranged from no payment at all, often for participation in support groups and some steering group meetings; increasing payment for consultation and steering input; higher rates for participation in workshops, conference, candidate selection work and assessment activities; and a higher rate still for joint teaching and direct student contact. Payments ranged from £0 to, at the highest, just over £60/hour. Eleven HEIs reported a policy of only paying expenses to carers (and service users). Figure 3.16 shows the extent to which carers were paid fees for their work.

In most of the HEIs where payments were made, they were on a par with the rates offered to professional staff for comparable work activities. Seventeen confirmed payment for teaching/student contact work and eight reported payment for consultation and advisory work. One HEI paid a carer and a service user different rates for the same work.
There was recognition that such payments were resource intensive:

“We had quite a battle at the beginning, but they are all now registered [on the university’s system] ... the hard core, so to speak ... are on visiting lecturer rates and on yearly contracts. And this is very expensive, there is no question, I’m just hoping we can keep this going.” (HEI coordinator)

However, there was also recognition that equal treatment was important in partnership work:

“For us, at the centre of how we work, is that we are seeing this as being a partnership, and if it’s a partnership then we must pay people the going rate. Because if we are not paying them the going rate then inclusively we are giving that message that this isn’t a partnership; we are not equally valuing you here.” (HEI coordinator)

HEIs often raised concerns about the impact of fee payments on carers’ benefits. And several interviewees reported that carers declined the offer of payment due to fear of loss of benefits. One HEI reported offering vouchers in lieu of payment in an effort to avoid concerns regarding lost income due to a withdrawal of welfare benefits.2

Carers were aware of the resource constraints, and also that withdrawal of benefits was likely in relation to the amount they earned through involvement work. They reported significant difficulties in negotiating the administration of fees, with an experience reported of benefits being withdrawn completely while awaiting resolution of a claim, forcing the carer to engage in lengthy appeals while attempting to subsist on zero income in the meanwhile.

2 Such a strategy is not viable, as vouchers are still regarded by the Department for Work and Pensions as income.
HEI staff, while sympathetic to the difficulties relating to benefits claims, were sometimes reluctant to engage on a case-by-case basis with these situations, and ultimately viewed this aspect of carers’ involvement as the carers’ responsibility to resolve, with the first respondent below referring to the need to protect time to get on with the ‘proper job’:

“The payment thing is fraught with problems, I mean I was speaking to one lady today and she said that ‘we wouldn’t claim anything because of our benefits’ and I said ‘well surely you can claim up to £20 a week’ but she said ‘no, no’; in their benefits situation they are not allow to claim anything otherwise it upsets their benefits totally. And I’ve had other people say that it is just not worth it, and then other people are concerned about pensions and tax and stuff. And they would really like us to look into all that but we’re not in a position to offer that because the benefits system is so complicated now and if I did that I’d have very little time to do my proper job.”

“That’s a huge issue actually, and you know I kind of hate it when people raise it ‘cos I know I’m going to have to say ‘well, I can’t really look into this for you, you are going to have to look into this for yourself’, which seems a bit rough when they are coming in to help you and you are landing the problem back on them.” (HEI coordinator)

One HEI, however, reported purchasing a series of consultation sessions for carers (and service users) in order to provide them with expert advice. Another had adopted a strategy of payments over the year as seen in Practice example 13.

Practice example 13

One HEI reported placing carers on yearly contracts and averaging their pay in an attempt to ensure each weekly payment did not exceed their earning allowance. However, the interviewee expressed concern that despite agreement with their financial department she believed the carer may have received payment in a series of larger instalments.

3.6.4.2 Covering the costs of access and support for carers

Practice in relation to supplementary access was also variable. While some HEIs expected carers (and service users) to cover the cost of their travel out of their professional fee, in line with their treatment of other professional visiting staff, the majority of interviewees (21) reported that they made separate claims for these expenses. Interviewees reported that travel costs could be very expensive, with carers (and service users) having to use more convenient transport such as taxis or accessible vehicles to meet their access needs. In rural areas it was noted that greater distance could have an inflating impact on these travel claims. Figure 3.17 shows the range of practices employed.
Several HEIs in addition recognised a potential concern carers (and service users) may experience with cash flow and have made various attempts to be able to reimburse travel expenses in cash. Many reported difficulties, however, in negotiating the conventional retrospective claim process employed by HEIs, in their attempts to secure cash payments. Two HEIs reported achieving agreement with their finance departments on this concern while three others entered into agreements from external organisations to act as a banking facility for this function, invoicing the HEI for reimbursement after each event. There were also instances reported of academic staff, sympathetic to the need but unable to find a way of securing a cash advance from the HEI, making reimbursement from their own resources, entering a personal retrospective claim to the HEI.

While all interviewees recognised the potential for carers to require additional practical support with regards to funding replacement carer costs, the HEIs were divided on how to address the concern. Sixteen of the interviewees reported on the methods they used to meet replacement care costs when encountered. Nine interviewees (seven HEIs and two externally led involvement groups) covered repayment through a fully declared claims form. Four programmes reported having to cover the costs of replacement carers by artificially inflating the hours paid for, while others were able to facilitate these costs within their expense claims. Two interviewees reported making arrangements to reimburse carers for expenses in cash. Three HEIs arranged for cash to be given by a local carers’ agency or other external agency that invoiced the HEIs retrospectively for these funds.

The majority of interviewees referred in varying degrees to the resource needs in supporting carers with broader practical access issues over and above those associated with reimbursement of expenses. This included the provision of:

- induction on, and orientation to, the HEI and the specific courses or practices
- practical support and advice in a human resources (HR)/personnel care capacity
- practical support and advice in a carers’ support worker capacity
• translation of academic papers into an appropriate language for carers
• language translation.

3.6.4.3 Meeting the resource requirements for development and maintenance of involvement work

The DH has continued to make funds available via the GSCC as a contribution towards developing and maintaining service user and carer participation in social work degrees and in PQ programmes. These funds are only a contribution towards overall costs. The GSCC recognises a substantial range of uses for the funds, as shown below.

Funding to support the involvement of people who use services and carers

To support the involvement of people who use services and carers in the design and delivery of social work degree courses, the DH has provided the GSCC with funding for grants to teaching institutions. Work undertaken by HEIs should include:

• consulting with people who use services and carers to make sure their needs and opinions are reflected in the design and development of courses;
• making sure the views of people who use services and carers are taken into account in the assessment process;
• involving people who use services and carers in important processes, including designing, delivering, developing and reviewing courses; and
• making sure that representatives of people who use services are involved in the selection process.

The grant can be used as a contribution to the costs of travel expenses, and/or systems to support the involvement of people who use services, such as the provision of interpreters, advocates or any other special needs which may need to be met. The money may also be used for the production of handouts or questionnaires.

Source: GSCC (2009)

While many of the HEI surveys were making careful use of the GSCC funds, they were often also drawing significant sums from a visiting lecturer budget to help meet costs of carers’ (and service users’) involvement. Over half of the interviewees (19) reported significant concerns about achieving successful development of involvement with the resources available:

“The GSCC grant covers the coordinator’s time and not a lot else.” (HEI coordinator)

The costs were recognised as quite substantial:
“... the involvement in all three courses, it is probably about two or three people full time, if you put them back to back.” (HEI coordinator)

“We have to be quite creative about the way that we use the resources that we have. One of the things are trying to do currently is to look at how we can get more out of what we are doing and what we’ve got.” (HEI coordinator)

Equally the demands on academic staff time were recognised:

“I could spend all day working with other organisations, just trying to get carers in....” (HEI coordinator)

A further demand on time arose when arrangements for carers’ participation sometimes fell apart, for understandable reasons from the carers’ point of view, but nonetheless causing difficulties in the context of a timetabled commitment:

“I think staff are worried about things like that, I mean if they set up a lecture and then it all falls apart what are they going to do about it?” (HEI coordinator)

External organisations and HEIs have to account for the spend:

“We have to basically justify the work that we do, in terms of when we apply for funding. So we need to be able to demonstrate to the sources of our funding that the work that we are doing is actually making a valuable contribution and is benefiting carers. We also need to be involved with the institutes like the local university and we need to be in key positions. We have over a thousand people on our database who (1) we need to support and (2) who can in turn hopefully influence change.” (external organisation representative)

However, there were hidden costs for organisations working closely with HEIs on this agenda:

“In all honesty the amount of time that I have put in, they would not be able to pay me. But when I have actually done work in contacting carers and written out letters and taken out carers to the university and that kind of thing then I have been paid. This work is outside of my job role and my manager has said ‘if you want to do it then you can do it’, but you have to get them to pay for your services and so then we have charged the university and they have paid us the hourly sessional tutor rate.” (external organisation representative)

For both HEIs and external organisations, in addition to continuous work on recruiting new participants, there was the need to maintain communication with partners as part of what the GSCC describes as ‘robust arrangements for collaboration’. Several HEIs reported maintaining strong contacts with external organisations with, in some cases, representatives being invited to participate in programme review boards. One external organisation, however, reported that collaboration had not been maintained beyond the carrying out of an initial awareness-raising and introduction event for the HEI, and once the HEI had recruited some carers the collaboration appeared to end,
indicating perhaps the time-intensive nature of ongoing investment in collaborative structures.

Interviewees from HEIs with several social work programmes and from social work departments embedded in health and social care schools with strong interprofessional carer and service user involvement reported access to greater resources and, of the HEIs surveyed, these establishments had involvement programmes which were substantially more extensive, and were able to explore innovative methods for engaging carers, such as acting as consultants for student workshops and participating in conference-style learning sessions.

It is clear that there are significant resource demands to ensure consistent engagement of carers in involvement activities. Successful partnerships with external organisations have helped here, sometimes drawing in the resources of those organisations where objectives of the organisation and of the HEI were compatible.

Nevertheless, the resource demands of participation have brought new and additional responsibility for HEIs, such as meeting the additional access expenses incurred by carers, ensuring of sufficient participants to maintain provision and meeting the communication and administrative costs associated with recruitment. Where involvement patterns have become extensive, as a result of successful development and good partnership practices, the costs have also risen, and routinely exceed the dedicated funding set aside for this purpose.

3.7 Working with carers and with service users together

The study invited interviewees and RCGs to consider whether there were any meaningful difference between carers’ and service users’ contributions to social work education activities, and if so, how to allow for these in the involvement of carers in social work education.

3.7.1 Perceptions of service users and carers

Central to the question of working with carers and with service users is the question of carers’ identity and location within the field of practice. Among participants, the study revealed only loose consensus in understandings of what it was to be a carer. These were far from consistent throughout the HEIs surveyed and indicate some variation in expectations about the roles social workers will have in engaging with carers in practice. Social workers were perceived by interviewees to attribute a range of identities to being a carer, shifting uncomfortably between being seen as:

- a user of services and therefore a client of social workers
- a member of an at-risk group, and therefore a client of social services
- an individual in their own right, with a human right to an equal opportunity for a reasonable quality of life
- a partner in the care of the service user (often perceived as being untrained, but with a greater capacity for time with the client)
- a consultant with expertise on the specific circumstances of the service user
- a potential abuser and cause for safeguarding concerns for the service user
• a surrogate voice, speaking on behalf of the service user
• a family member
• a participant in maintaining a psychological situation which prevented the service user from attaining greater independence
• an unrelated bystander in the relationship between a service user and the social worker.

While we found some understanding of these shifting identities, and of their significance for carers’ participation in social work education, the study found no evidence of a clear strategy to address what the implications in relation to student learning might be. The study found many instances where interviewees and RCG members stated that they perceived ‘no difference’ between service users and carers:

“After all I see myself a service user because I am only trying to access the same services for my loved one.” (carer)

But equally there were several instances where attempts to involve carers and service users together had manifested tension and in some cases overt conflict which could surface in the classroom. Eleven interviewees and several RCG members reported incidents of tension and in some cases conflict emerging over differences in attitude and points of view between carers and service users, as the following three quotes highlight:

“I suppose it is a slight change of emphasis. They are not actually in receipt of the care, they are involved in the delivery of it from a third party point of view.” (HEI coordinator)

“I’m thinking of a mother with a very injured child, she was telling us about what happened to her and her girl, who had very little speech, was sitting there, she could interject a bit but not a lot.” (HEI coordinator)

“Conflict is like the bread and butter of social work, in relation to, like, people wanting to take risks, so that makes a big difference, where you identify that the service user’s at risk. Where people are taking a rather unusual approach to managing unusual behaviours related to someone on the autistic spectrum disorder – deciding that one of the ways to prevent someone from behaving in a certain way would be to slap the young woman – this leads to somewhat unfortunate conflicts of interest, you know.” (HEI coordinator)

One strategy was to offer the service user and the carer involvement at different times, as shown in the next two examples:

“Carers might want to share some negative comments about the service user because of the dark thoughts that come with caring, they might not want that caring role.” (HEI coordinator)

“I was talking to a girl just recently who is physically disabled, and she feels very strongly that her family has held her back. Her values and her dreams, her goals, her parents were stamping on, and she has great anger for that.” (HEI coordinator)
But this could run into difficulties:

“I did bring it up, alluding to the fact it might be easier if the carer was there on her own, but the response I got from both sides was that ‘there are no secrets between us’ which is interesting because I knew that wasn’t wholly so.” (HEI coordinator)

The range of challenges reported as surfacing during participation included:

• carers reported feeling obliged to take on a caring role for the service users involved in the programmes
• service users feeling patronised by carers
• conflict which was described as abusive to the carer based on the service user’s denial of any needs while at the same time accepting carer support
• a complete refusal from service users to do any work with carers
• reports about carers and/or service users dominating shared group meetings in equal measure
• service users feeling their wishes were overruled by those of the carers, born out of the carers wanting to be considered co-workers in their care
• service users feeding back that they would not have made certain comments if a carer were present
• carers dealing with a sense of bereavement at the loss of the service user’s full capacity.

There were some examples of where involvement coordinators and/or academic staff were attempting to address these differences, which of course are there in social work practice as well as in involvement activities:

“There are just as many relationships in the world as there are in between a carer and a service user.” (HEI coordinator)

One example was where carers’ and service users’ involvement groups were separately organised, as shown in Practice example 14.

However, there were other more promising examples where carers and service users were involved in working together in joint presentations to help students gain awareness of potential or actual conflicts of interest, as shown in Practice example 15.

### Practice example 14

“A number of carers prefer the MA carers’ project because it’s a carers’ group. I am picking up that there is some feeling that some carers do not want to be involved with a service user group because their needs are very different and they perceive them in a different way and also, interestingly it’s an issue we’ve picked up from the service users.”

This kind of practice would require a confident carer and service user experienced in involvement activities, probably ‘embedded’ within the programme and therefore familiar with its aims and educational practices, together with an academic who
was alive to the issues, willing to risk the expression of conflict and difference in the classroom and to not only debrief the carer and user should it be necessary but also the students.

3.7.2 Engagement with difference

Over half the interviewees for the study reported utilising a reference or consultation group comprised of a mix of carers and service users. During the course of the study several interviewees described episodes where carers and service users modified or withheld comments because of the mixed nature of the group membership.

The study also discussed, particularly in the RCGs, the phenomenon of the intricate and complex relationships that form between carers and service users, which were seen as sometimes including aspects of denial, complicity and co-dependency. The apparent and not uncommon incidences of reported belief among carers, involvement coordinators and associated academic staff that there was no significant difference between carers and service users seems incongruent with these observations. This indicates that the push for consensus and an emphasis on what people hold in common is strong and that the wish to avoid conflict and divergence may mask other more contentious factors of power and diversity which could more usefully be explored.

It would appear that social work education would benefit from creating more space to explore the similarities and differences between carers and service users, perhaps engaging carers and service users from different caring situations in order to replicate the relationship between carers and service users in a way that manages the risk to participants, and to enable students to engage with the complexity of the personal and professional relationships involved. The following statement by an HEI coordinator might indicate an implicit view that there is a hierarchy between users and carers, related implicitly to an assumed hierarchy between service users and professionals.

“They, the students that is, can’t quite address how to deal with carers because they tend to default to the position that treats carers as service users. And carers
are absolutely adamant that they are not service users, they want to be treated as equals with the professionals.” (HEI coordinator)

One would expect that student views of this nature would be challenged from the perspective that both service users and carers should be treated as equals by professionals.

Exploring the role of a carer in a care situation needs to be carried out with sensitivity to the intricate and complex web of relationships between carers and service users, with the goal of establishing greater clarity and understanding to enable involvement workers and ultimately graduating social workers to successfully negotiate these issues for better outcomes.

3.8 Enquiries to support the development of a web tool

The study invited interviewees to report on past and current use of the internet to support their involvement activities, and to express their interest in the development of a web tool. The study also invited RCG participants to explore the functions and topics of such a web tool to inform ongoing development work.

3.8.1 Current and past use of the internet to assist involvement of carers in social work education

The most common uses of the internet identified by interviewees were to:

- support communication with carers, enabling people to participate in discussions and meetings from home
- carry out research to inform development of local carers’ involvement work
- help develop links with relevant partner organisations.

Three interviewees reported that they were in the process of developing local websites for carers (and service users). Three reported using the web to support orientation and training of carers, through accessing guidance and using e-learning programmes.

Some interviewees expressed some concerns about their use of the internet:

- that given there is often only limited time available to carry out effective searches, respondents were therefore reliant on easily available material
- that respondents have noted a significant amount of apparent duplication of material, produced in apparent isolation by organisations such as Care Services Improvement Partnership (CSIP), S4C and SCIE
- that regarding web development there is some concern about the ethics of providing access to material, even with some restrictions of use via the web.

3.8.2 Extent of interest in the development of a web tool

Twenty-five interviewees expressed positive interest in the development of a web tool by SCIE. Some interviewees reported the following concerns, however:
that the majority of carers are not regular web users and therefore recommend the production of some parallel facility for non-web users
• that, given the vast scope of information potentially available, access needs to be quick and easy for the user
• that any facility must be relevant and exciting to the carers/users
• that a review of usefulness of the web tool facilities and contents be carried out regularly – to verify value of the web tool or to inform future development
• that local identity is important as carers are often quite isolated.

3.8.3 What functions and topics should be covered by the website?
Twenty participants suggested information on how to develop carers’ (and service users’) participation should be an important function for the web tool. This included:

• links to relevant organisations (such as potential partners and other participation practitioners)
• case studies about best practice and analysis on failed initiatives;
• guidance, advice and information on how to carry out carer (and service user) engagement.

Thirteen participants called for tools to support delivery of teaching practice, including:

• storage for and access to reusable learning objects (such as video interviews with carers)
• guidance/advice on how to look after carers (and service users)
• support to students for further study.

Ten participants suggested tools to support carers to participate, including:

• facilities for carers to get involved from a distance (eg from home)
• provision of background information to carers (such as relevant academic aims, shared values etc)
• facilities for promotion of group identity and peer support.

Nine participants suggested that information on how and why HEIs should develop carer (and service user) participation should be included. This would include:

• SCIE/GSCC guidance on policy and practice regarding carer (and service user) participation at the point of teaching
• academic information (such as appropriate learning outcomes for use by carers within specialist modules/units.

Participants in the RCGs identified the following topics for the web tool:
About social work:

• Definition of a social worker
• A list of social care courses
• Basic outline of social care courses
• Breakdown of units that social workers have to study
• No jargon (glossary)

About getting involved:

• Example of an ideal model of participation
• Latest ideas and innovations: somewhere to get feedback from what other people are doing and where, with contact details
• Ideas of level/tiers of involvement (not always resource heavy)
• Case studies, such as following someone through their involvement
• Other people’s experiences, perhaps through blogs/diaries
• What’s out there and what the website user can seek to get involved in?
• Links with other organisations and university websites
• Degree courses to become specialist, inviting people in many different capacities
• GSCC information, including guidelines for types of involvement and possible funding
• Possible sponsors
• Current issues (such as ‘baby P’, topical at the time of the groups)
• Tips from other carers experienced in social education

Specifically for carers:

• A carers’ page
• Something which explains what a carer is, something people can relate to and identify if they are a carer
• Resources/limitations and criteria for involvement – criteria that show you don’t have to be an ‘expert’
• Tips from other carers experienced in social education
• Going with an experienced carer the first time
• Benefits of getting involved
• Issues around involvement
• Is involvement right for me?
• Support and what to expect
• How to get involved
• Time implications
• How much of your story should you tell? How much is related to the programme?
• Training for involvement (e.g., presentation skills)
• Provision of training – needs/expectations
• How to challenge the local university regarding the model of involvement
• Contacts
• List of agencies – local/ national
• Information regarding funding for replacement care and other support
• Good links page to carer groups such as The Princess Royal Trust for Carers, Carers UK, national charities and fostering networks

56 Carers as Partners (CaPs) in social work education
• How to access the support and resources you need
• Discussion areas so people can comment and ask questions
• Where you can get free internet training
• Training centres and locations
• Benefits and payment/implications of payments – benefits guidance
• Travelling expenses
• Legislation, for example the Carers (Equal Opportunities) Act 2004 and policy framework for involvement
• Link to rights, information and support for carers
• Chat room for carers, for example to ask questions and find answers

About young carers:

• About young carers
• A place to approach young carers
• Maybe have a young carers’ page

Other topics:

• National and regional events
• A good forum for surveys, and how well carers are supported
• FAQs
• Discussion forum
• Include healthcare concerns
• Radio station access, key note speakers, like podcasting
• What different programmes are going on nationally/locally
• Discussion areas where topics can be generated by different regions
• Personalisation – carers’ agenda
• Different languages (translation)

The participants at the RCGs identified the following functions/topics as priorities for the web tool (the order of this list does not indicate any relative priority):

• information page, and forthcoming events
• case studies, such as following someone through their involvement
• how to get involved
• something which explains what a carer is, something people can relate to and identify if they are a carer
• latest findings and updates on current issues such as baby P
• feedback about the site.

3.9 Future participation

There is clear interest in involvement in taking participation forward in the future, with all of the HEIs, 90% of the external organisations and all of the participants of the cluster groups (who expressed a preference) stating a wish to be linked into future developments arising from this project.
Just under half of the interviewees (15) in the mapping phase expressed an interest in incorporating or building on the work of an existing RCG, with a clear interest in sharing and widening knowledge about practice (seven interviewees) and even engaging in collaborative policy and strategy development work (six interviewees). This would build on collaborative networks already established by HEIs on other aspects of social work education, as shown in Practice examples 16 and 17.

**Practice example 16**

“We've always had very close links between the HEIs and all the local authorities within the region. We meet regularly and we have a common assessment documentation for placements, common approaches to the whole placement process just to make the whole thing that much more workable.” (HEI coordinator)

**Practice example 17**

“... here we have, I think it is now 11 years old, a regional social work network which is a very vibrant group of HEIs and employers. Service users are joining it, and Skills for Care come, for example. It's a very useful forum for discussion and shared planning.” (HEI coordinator)

However, where groups and networks already exist the study found some notable concerns about organisational capacity for such initiatives, with one regional group reporting genuine concerns for the continuation of a successful group due to a change in the host organisation's priorities and therefore a lack of funding.

Where there did not appear to be a group to support carer and service user involvement in social work education, interviewees expressed concerns about finding the necessary organisational lead and capacity to do so. However, one HEI that had expressed an interest in leading a regional forum was not able to identify funds to resource it to do so.

RCG participants were asked to map out the HEIs they were involved with. Information about other carers’ organisations in the region has been added. An example of a regional network that emerged is presented below (Figure 3.18), showing complex and extensive relationships in operation.

Figure 3.19 shows the regional network with all the local carers’ organisations included. This model could indicate a way forward for regional networking which would support wider access to carers and greater sharing of resources.
Figure 3.18: Example of map of a regional network

Regional Cluster Group: West Midlands – Carers’ groups and HEIs

Abbreviations:
- HEI: Higher Education Institution
- PRTC: Princess Royal Trust for Carers’ centre
- Crossroads: Crossroads Association centre
- Carers UK: Carers’ centre listed by Carers UK (not aligned to PRTC)

Key:
- Connection to ...
- Further connection to ...
- (Unable to attend – apology received)
Figure 3.19: Example of map of network including all carers’ organisations in the region

Regional Cluster Group: West Midlands – Carers’ groups and HEIs

Abbreviations:
- HEI: Higher Education Institution
- PRTC: Princess Royal Trust for Carers’ carers’ centre
- Crossroads: Crossroads Association centre
- Carers UK: carers’ centre listed by Carers UK (not aligned to PRTC)

Key:
- Connection to ...
- Further connection to ...
- (Unable to attend – apology received)
4 Conclusions and recommendations

4.1 Clarity of definition

The term ‘carer’ is much discussed in the extensive literature on caring. In this study, if defined at all by participants, ‘carer’ is subject to different definitions. Whereas there is no guarantee that greater clarity would lead to enhanced practice, judgements about carer involvement could more easily be made if the term was clarified. The definition used in this study and drawn from the Wales Care Council provides a useful start.

Recommendation: Programmes should consider developing their own explicit definition of ‘carer’ that would be included in programme documentation, enabling judgements about carer involvement to be more easily made. GSCC might have a role in monitoring such definitions.

4.2 Nature and range of ‘involvement’

‘Involvement’ ranged from consultation with carers to carers reporting feeling ‘embedded’ in programmes. The terms ‘partnership’ and ‘networks’ were prevalent. ‘Partnership’ practice is, like ‘carer’, another term that is under-theorised as it relates to social work education. This is discussed in some depth in the SCIE knowledge review of partnership work in social work education (Taylor et al, 2006), where aspects of partnership with carers (and service users) were explored. ‘Networks’ have a particular meaning in carer involvement as they provide support to carers who engage in different kinds of involvement activities. We heard of networks under threat due to lack of ongoing funding, an issue that will require creative attention in times of economic restraint.

We found that carers were involved with a broad range of activities on social work education programmes:

- recruitment and selection of students
- teaching and learning
- assessment
- programme management.

Given the range of programme size, structures and focus, it would not seem advisable to seek a uniform and prescribed allocation of carer involvement across the above activities but the balance of activity needs to be monitored.

Recommendation: If carer involvement is to be systematically embedded, it would seem appropriate that the GSCC monitors the balance of activity across the range of possible types of involvement (eg recruitment, teaching, assessment, management), and expects there to be an underpinning rationale for the patterns of involvement observed.

Recommendation: Programmes should monitor and review levels of carer engagement across the range of possible types of involvement, and develop strategies and action
plans to strengthen and support involvement in aspects of social work education where it is not already taking place.

Recommendation: Programmes should recognise the need for different types of skill development related to the specific activities undertaken by carers (eg interviewing, teaching, assessing written work and/or practice portfolios), and provide access to the specialised types of training and support necessary.

4.3 Specific areas of involvement

4.3.1 Recruitment and selection of students

The project found some concern about the difficulty of maintaining a fair and equitable interview practice for all candidates, especially in the context of carers being unable to fulfil their commitments to attend sessions. There were also significant logistical and resource barriers to supporting sufficient numbers of carers to participate in interviews. Equally, problems arose for carers from changes of date and last minute cancellations. Some programmes have begun to develop strategies designed to address these issues, and this work would merit further exploration and development.

Recommendation: Further exploration and development of student recruitment and selection practices is required in order to promote wider carer participation while maintaining fair and equitable interview practice for candidates.

4.3.2 Teaching, learning and assessment

Carers are involved in the design, delivery and review of teaching and learning across a range of modules and most often in modules to do with awareness of, and working with, carers, communication and listening skills and preparation for practice. Carers’ perspectives were also deemed relevant by some HEIs across other areas of the curriculum, and three programmes had decided carer involvement was relevant across all modules. Individual programmes might consider their rationale for carer involvement in teaching and learning and examine how this might be further developed beyond those core areas identified above.

Carers are contributing to the design and delivery of assessment of student work in the classroom, most HEIs commonly enlisting carers to observe and provide feedback on student presentations. In some instances, involvement includes grading. Typically the scope of assessment appeared to be restricted to student understanding of carers’ issues but interesting examples were found of carer involvement extending beyond knowledge or expertise about carers’ issues.

Assessment is a site of power in the university and there were evident barriers to carer involvement, including, for example, HEIs who would not support this activity, and the perceived lack of carer confidence and requisite skill and understanding in participating here. The issue of carer (and service user) involvement in assessment would merit further focused study.
Recommendation: Programmes should consider their rationale for carer involvement in teaching and in assessment of students, and examine how this might be further developed, including beyond those core areas identified in this report.

4.3.3 Programme management

There was some conviction about the value of carer involvement in programme management and interesting examples of this being implemented, as well as examples of local resistance. It is difficult to know how much effect carer involvement has on programme boards and advisory groups and indeed this raises a question of how much of the curriculum could be informed by reference to carers (and service users), and to what degree the management processes of an academic activity can be shared with other stakeholders.

4.3.4 Involvement beyond programme level

While it would seem that carers’ involvement coordinators, and in particular the carers themselves, have a potentially crucial role in brokering genuine power sharing in social work education, it would seem that service users were better represented than carers at a lobbying level, both locally and nationally. While this study found many incidences of carers’ support organisations, the study found fewer indicators of carer representation with regards to lobbying for carers’ rights within the social work education industry. The need to lobby for carers’ rights in social work and social work education has emerged as a priority from this study.

4.4 Recruitment of carers and support for their involvement

HEIs use a variety of strategies to recruit carers and have different objectives, including seeking to recruit carers with capacity to work effectively in a teaching environment, while others emphasise recruiting carers with an authentic voice. Good use is made of community contacts in initial recruitment activities; however, engagement with local centres then appears to drop off when it would appear they could offer ongoing carer engagement and support.

Some programmes had successfully established links with a wide range of more seldom-heard carers. Those HEIs with higher black and minority ethnic representation reported strong links with carers’ centres that may indicate a route to improving black and minority ethnic representation.

Very little success in engaging directly with young carers was reported, consistent with findings from another recent study of engaging carers (and users) in learning and teaching about integrated children’s services (Taylor et al, 2008). There were examples of innovative approaches to engaging young carers, including developing the use of reusable learning objects (DVD and video) that would seem an important way forward.

The basis of selection of carers was varied, notably between HEIs with the view that carers must have appropriate training or skills to become involved and those who deemed it appropriate to enlist any carer who applied. Interestingly very few HEIs...
had a specific selection policy which for equal opportunities reasons merits further attention.

There was widespread concern about the barrier to carer involvement posed by limited resources. This is a pressing issue particularly in times of severe economic restraint and requires careful and considered attention by the stakeholders involved, and possible liaison with carers’ centres about rationalising roles and responsibilities.

**Recommendation:** Given the importance of equal opportunity concerns, programmes should consider developing a recruitment and selection policy that can be publicised to carers and carers groups. This should include further clarity on the different purposes of participation and the skills and experience sought from carers.

**Recommendation:** Programmes should consider how to extend the range of carers involved and in particular take action to secure the involvement of more seldom-heard groups, including young carers.

The scope of provision of carer orientation, training and support among the programmes surveyed was broad and diverse. Key issues identified, which signal the need for training and support, include (i) being oriented to practical issues such as the location of teaching rooms, making sure that claims are processed appropriately, etc; (ii) recognition of support for people who may be talking about very personal and stressful matters and who may need a follow up and debriefing; (iii) training in relation to specific activities such as assessing portfolios or presentations; and (iv) student feedback to carers about the value of the carer activity, and included in this could be matters such as employment destinations of students when they graduate.

**Recommendation:** Programmes should consider the need for written protocols and ethical guidelines for involvement activities. Such guidelines might include the recognition of the potential personal impact of involvement and the provision of support where necessary to address this.

**Recommendation:** Careful and considered attention to be given by the stakeholders involved to providing adequate resources to induct, support and sustain carer involvement.

### 4.5 Management of carer involvement and carer involvement coordinators

Management structures inevitably vary and may involve heads of programmes and/or liaison with a steering group.

Carer (and service user) involvement coordinators in many cases exercised a significant amount of influence over the nature and progress of carer involvement in programmes. There are four different models of carer coordination: (i) coordinators sited in and employed by HEIs, thus enabling communication with academic staff (possibly combined with taking responsibility for service user involvement); (ii) coordinators working in close partnership with (possibly extending to partial co-location in) carers’ centres to allow better communication with the wider
carers’ community and access to support services for carers; (iii) carers’ centres commissioned to provide coordinators; and (iv) other organisations, independent of carers’ centres, providing support to carers during their participation in social work education. These models may provide examples for programmes that still need to develop structures for the organisation of carer involvement.

The level of responsibility exercised by involvement coordinators was not always recognised, or based on a formal appointment procedure and job description.

Recommendation: Programmes still needing to develop structures for the organisation of carer involvement will find it useful to draw on models found in this study. In particular, dedicated and ring-fenced staff time, whether academic or contracted elsewhere from within a carers’ network or organisation, is helpful in taking forward the involvement agenda.

Recommendation: Involvement coordinators should be supported by a contract that is based on a formal appointment procedure and job description.

4.6 Resources to support carer involvement

The issue of resource to support carer (and user) involvement has been widely discussed and the range of issues will not be rehearsed again here. Two key points specific to carers are important.

(i) A key difference in support for carers from that for users is that carers are typically responsible for a cared-for person and may have to pay for the costs of replacement care as well as negotiate the often complex emotional issues involved in leaving the cared-for person with another. This issue requires both financial resource and recognition.

(ii) Carers may be in receipt of financial benefits that may complicate payment transactions. Whereas this long-standing and seemingly intractable issue needs to be resolved, an interim measure which is acceptable to some carers who are part of carers’ organisations is for payment to be made to an external organisation charged with dispensing payment to the carer in a way that does not penalise the carer. However, further high-level work is necessary to remove some of the barriers to participation that arise from welfare benefits rules. This needs to be undertaken at national, rather than local, level. Equally, guidance for programmes about how negotiation within local benefits rules flexibilities can produce useful local agreements, and which reassure carers, would be a helpful intervention.

Recommendation: The stakeholders in social work education must give careful and considered attention to the need for secure and adequate resources to induct, support and sustain carer involvement, including resources to support the work of carers’ centres in encouraging and supporting carer involvement.

Recommendation: The costs of any replacement care required in order to facilitate carers’ involvement must be resourced.
Recommendation: Further high-level work is necessary to remove some of the barriers to participation that arise from welfare benefits rules. This needs to be undertaken at national, rather than local, level. Equally, guidance for programmes about how negotiation within local benefits rules flexibilities can produce useful local agreements, and which reassure carers, would be a helpful intervention from the DH.

4.7 Working with carers and service users together

There are different and diverse perspectives on what it means to be a carer and what it means to be a service user, both within and between the respective groups. It is important that HEIs recognise the differences and do not treat carers and service users as if they are interchangeable, although the significance of the differences will vary according to the activity in question. Given that students studying to be social workers will be working with these differences in placement and in qualified practice, it would seem important to explore the different perceptions which at times may present as sources of tension and/or conflicts of interest between carers and service users. These are not easy to acknowledge openly in the classroom and will need careful preparation and support from the module convenor and the carer and service user coordinator(s) – but being able to acknowledge these issues in the relative safety of the classroom would seem an important step to being able to do so in practice. Equally, within programmes themselves, there could usefully be stronger recognition and accommodation of difference in the interests of service users and carers, and in the mechanisms and structures for developing and managing involvement.

It is important for qualified practice that students have the opportunity to explore the differences between carers and users that at times may present as sources of tension and/or conflicts of interest. Programmes might develop mechanisms and structures for developing and managing this work.

Recommendation: It is important for future practice for students to explore the different perceptions and perspectives that at times may present as sources of tension and/or conflicts of interest between carers and service users.

Recommendation: Managing such differences needs careful preparation with students, carers and service users, and support for those involved. Programmes should develop mechanisms and structures for developing and managing this work.

Recommendation: If the involvement coordinator role combines responsibility for carer and service user involvement, the issue of balance and recognition of similarities and differences between the two groups is important to monitor and maintain.

4.8 Next steps

This study focused on the experience of carer educators, and of academic staff working with them in the HEI context. The experience of students with both carer and service user educators merits further research, as does the question of outcomes. It is important to move beyond a belief that it is a ‘good thing’ to understand what is effective and what impacts can be observed in relation to the skills, attitudes, confidence and ultimately practice of qualifying social workers.
The potential value to social work practice of student learning from exploration of the differences between carers and users has emerged as an important issue. How this might be further developed and the implications of doing so for carers, service users, students and academic staff merits further research.

The value of partnership work between HEIs and national and local carers’ organisations emerged as significant to the development of carer involvement in social work education and one that could be significant in lobbying for carers’ rights. What are the enabling factors and what are the barriers to such development?

Recommendation: Research is required into the outcomes of carer participation in social work education, to include outcomes for students, the academic faculty and carers themselves. Particularly pertinent will be research into the impact on students’ practice.

Recommendation: Research is required into the design and development of forms of carer and user participation that explore differences and similarities in perception, attitude and beliefs.

Recommendation: Research is required into the potential for, and models of, partnerships between HEIs and national/local carers’ organisations, and their role in promoting and sustaining carer involvement in social work education.
5 Reflection

This study has been the first national study to focus on carer involvement in social work education, treating this as an issue separate from the involvement of service users. The project team built on their now considerable experience of undertaking knowledge reviews of aspects of social work education. Given the limited resource available for the study, the research approach was effective in gathering a breadth and depth of data and providing a new and original insight into carer participation in social work education. The RCGs proved enormously productive as well as stimulating for the participants. The study was also effective in linking to national and local carers’ organisations, as reflected in comments below from some steering group members, and discovering some of the benefits of partnerships between those organisations and the HEIs.

There were inevitably some limitations to the study. Reaching seldom-heard carers and involving them was difficult. It might have been illuminating to explore the position of academic staff who were also carers. Students were not involved because the focus was on carer educators, but clearly student responses to carer involvement, and the outcomes for their learning, are crucial aspects on which to develop further understanding.

One of the distinctive features of this project has been the close collaboration within the steering group of different stakeholders, and in particular the role played by the carers’ organisations. We therefore conclude here with a reflection on that involvement, from the perspective of those organisations involved, and on the potential for the ongoing partnership between carer and user involvement coordinators and external organisations. These perspectives are quoted here in full to underline the future possibilities:

“My role in this steering group has enabled me to revisit feelings I had about social work training in relation to carers. This was based on my own experience of completing a social work degree, participating in carers’ services as a student and my employment in voluntary sector carers’ services. I have gained knowledge about the current levels of carers’ involvement in national training from the carers and professionals I have met via CaPs. More importantly I have learnt what works well and in which areas there appear to be gaps. I feel encouraged to pursue the promotion and support of carers’ involvement in social work training in my area. I have begun to pursue links with the local university.”

“I enjoyed being a member of the steering group. I felt I was able to contribute to the shape and delivery of CaPs and that the involvement of The Princess Royal Trust for Carers was valued. I appreciated the way the professors of social work and social care and the project research associate at the University of Sussex enabled meaningful involvement by all steering group members, which was particularly important, I think, given the focus of CaPs, and the project benefited from the equal weight and respect accorded to a variety of viewpoints and expertise. I was able to learn from and debate with others, including carers, about what works to engage carers in social work education and the positive impact that engagement can have on partnership work between social workers, carers and service users.”
This learning will be applied and shared to inform the work of The Princess Royal Trust for Carers. I’m looking forward to seeing what carers showed and told us being put into action through the dissemination and development of CaPs.”

“This report will be disseminated to all 144 independent carers’ centres working in partnership with The Princess Royal Trust for Carers across the UK. Information on the GSCC guidance to social work programmes about carers’ participation will be sent to all carers’ centres, and centres will be supported in engaging with local HEIs.”

“I was asked to be involved in this research project on behalf of Carers UK. I joined the steering group at a stage when a lot of the work had been undertaken. My overall impression of the project is that it was very well coordinated and run. I was particularly interested in the findings of the initial research into the level of individual colleges' commitment to the requirement to involve carers and service users in all aspects of social worker training – from very good examples where there was a dedicated member of staff to coordinate the volunteers and liaise with the curriculum teams and training staff to a very cursory ‘lip service’ being paid to the requirement. It would be really good to see all colleges seeing not only the benefits, but how crucial this input is in terms of developing meaningful engagements and working relationships with the people they will be serving, once they are in office. As the move towards the personalisation agenda quickens, there is the expectation that service users and their carers will be much more involved in determining their lives and the choices they make in terms of care and support; increasing the need for their involvement not only in the training of social workers, but in other areas of the delivery of social care.”

The strength of commitment to partnership is striking, as is the aspiration to ensure that through such partnership the social workers of the future, now being educated and trained for their role, are able to embrace change in the power relations of service provision. The last words should perhaps go to a participant who reflected on the overall purpose of the work in which all those contributing to social work education, from whatever perspective, are engaged:

“It’s about investing for the future really, because if we can get the right buttons pushed early enough then that may change practice for a whole group of people for the better. And I am sure that’s the objective.”
References


GSCC (General Social Care Council) (2002) Accreditation of universities to grant degree in social work, London: GSCC.


Wenman, H. (2005) Working towards full participation: A report on how social work degree courses, which started in 2003, have begun to involve service users and carers in social work training, London: GSCC.
Appendix 1: Terms of reference

Agreed by project steering group 14 October 2008

1. Title of group:

Project steering group (PSG)

2. Purpose

• Give guidance on processes, contacts and other aspects of the project.
• Give guidance on the environment in which the project is set.
• Inform project management and project work on issues and perceptions current in represented agencies that are relevant to the successful delivery of the project.
• Provide an ‘ideas pool’ to inform design and delivery of the project.

3. Outputs

• Amendments to project programme (e.g. objectives and work tasks) as required.
• Contribute to the evaluation of project progress at each stage.
• Information and guidance to project programme as required.

4. Scope

For the purposes of this project:

Carers are people who support family members or friends who need care, help or support. Carers can be adults caring for other adults, parents caring for ill or disabled children under the age of 18 or young carers under 18 who care for another family member. There is not a typical carer. Carers may be of any age, culture or religion, and from a diverse range of backgrounds. Some carers do not see themselves as carers, but primarily as a parent, child, wife or husband, partner, friend or neighbour.

5. Membership

• Imogen Taylor, Professor of Social Care and Social Work, University of Sussex
• Andy Cheng, Research Fellow, Social Work and Social Care, University of Sussex
• Suzy Braye, Head of Department, Social Work and Social Care, University of Sussex
• Jill Pay, carer and Carers UK representative, also member of the Standing Commission on Carers and training coordinator, Camden Carers Centre
• Beryl Cross, The Princess Royal Trust for Carers representative, development manager (South East)
• Jenny Leitch, head of partnerships and external relations, Crossroads Care
• Jill Scholl, carer and Sussex and Brighton Universities Social Work Education Participation (SWEP) Project
• Tizzie Coleman, carer
• Sarah Hancock, carers’ development worker, primary and community care
• Debbie Charman, Strategic Commissioning Manager, Carers Adult Social Work, East Sussex County Council
• Hilary Burgess, Senior Academic Adviser, SWAP (Higher Education Academy Subject Centre for Social Policy and Social Work)
• Pete Fleischmann, SCIE representative
• To be nominated – representatives of other agencies/concerns as occasionally co-opted as required

6. Meeting arrangements

Joint chairs: Jill Scholl and Imogen Taylor

Location and venue: Initial meeting shall be at the University of Sussex hosted by the School of Social Work and Social Care; subsequent meetings by agreement of participants

Frequency: It is envisaged that the steering group will meet on three occasions to correspond to the key phases of the project. These are:
1. Set up and mapping, 14 October 2008
2. Consulting and communicating, January 2009
3. Analysis/reporting and conference, April 2009

Duration: Insofar as possible meetings should not exceed 90 minutes

7. Remit and responsibilities of members and member agencies

Each agency is responsible for monitoring the performance of its own representative. Where members represent organisations/networks, they will take responsibility for establishing two-way communication with those they represent, and for furthering the work of the PRG within their organisation or network.
Appendix 2: Survey guide: educational professionals

Carers as Partners (CaPs), a SCIE-commissioned carers in social work education project

(This draft: 23 October 2008)

This guide is for interviews with educational professionals involved in work including carers in social work education. It is to aid the telephone interviews in the mapping phase of the project. It is essentially a set of subject headings to aid the surveyor in getting data on all topics that have been identified as crucial to this project.

Brief notes and key advice for the interviewer

Method and style

• Where possible, carry out the interviews as a friendly and enquiring conversation.
• Where possible, make contact with interviewees to book a time to carry out the conversation. Advise the interviewee of information in the above steps at the time of booking.
• Introduce yourself and the project.
• Identify the project as: Carers as Partners (CaPs), a SCIE-commissioned project about carers in social work education.
• Ensure the person you are interviewing is appropriate for this enquiry (see ‘1 Who you are’).
• Reassure the interviewee that the duration of the interview will be limited (approximately one hour). (Give the option to continue should the interviewee wish to do so and the data is relevant to the enquiry.)
• State the purpose of this survey.

Purpose of enquiry

Project aims (agreed with SCIE)

1 To identify and report on the ways in which carers are involved in social work education
2 To identify the challenges encountered
3 To identify and promote the exchange of good practice
4 To explore how participation can be widened to include seldom-heard carers’ groups.

Consent and confidentiality

Note: If recording the conversation, secure consent prior to beginning recording.

Inform the interviewee that the recording/notes of the conversation will only be used for the purpose of the study and will be disposed of at the end of the project.
Inform the interviewee that we will not identify respondents by name or higher education institution (HEI) without their specific consent. We will only be seeking this with regards to practice examples, where we will provide them with the draft text for approval prior to publication.

**Closure of interview**

Ensure the interviewee is aware of contact details for this project.

**Headings**

<table>
<thead>
<tr>
<th>1 Who you are</th>
<th>4 Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 Who the carers are</td>
<td>5 Enabling processes</td>
</tr>
<tr>
<td>3. Nature of involvement</td>
<td>6 Significant barriers</td>
</tr>
<tr>
<td>3.1 Teaching</td>
<td>7 Future participation</td>
</tr>
<tr>
<td>3.2 Assessment</td>
<td>8 Recommendations for further contact</td>
</tr>
<tr>
<td>3.3 Recruitment and selection</td>
<td></td>
</tr>
<tr>
<td>3.4 Programme management</td>
<td></td>
</tr>
</tbody>
</table>

**Guidance notes**

1 **Who you are**

*Key information:*
Name:
Role (job title of description):
Relationship to HEI (eg lecturer with specific responsibility for carers, service user and carer development worker, charity sector partner, etc):
May also be a carer and may wish to say so?

2 **Who the carers are**

What definition of a ‘carer’ are you using (if any)?
Inform interviewee that, *for the purpose of this study we are using this definition:*
Check that it is appropriate to continue this interview.
Number of carers involved?
Which area(s) of concern carers represent:
Represented/not represented, for each:

3 **Nature of involvement**

Areas that carers are involved in, how they are being used and how well established they are.

Please tell me about how carers are involved in:

3.1 **Teaching**
- Design of module(s)
- Delivery of teaching session(s)
- Evaluation (monitoring and review)
Key information:
Activity:
Frequency:
Noteworthy results from evaluation:
Development (resulting from evaluation):
How well established:
Willingness of programme colleague(s):
Possible examples
• Carers help in identifying aims and learning outcomes
• Carers recruited to act as simulated clients
• Carers are brought into seminar discussions with students

3.2 Assessment
• Design
• Delivery
Key information:
Carer is contributing to a grade for the student or simply to provide formative feedback.
Acceptance by other colleagues?
Possible examples
• Carers in exam boards

3.3 Recruitment and selection
3.3.1 Interviewing individual applicants
• Design
• Delivery

3.3.2 Group interviews
• Design
• Delivery
Key information:
Carer contributing to selection or providing formative input.
Possible examples
• Carers help draw up candidate specification and suggest interview questions
• Carers are represented on the interview panels

3.4 Programme management
Key information:
Participation in programme (eg BA or MA) committees or boards:
Participation in course review or boards (eg specific modules):
Possible examples
• Carers attend senior management team meetings
• Carers attend planning meetings
4 Rationale
What are the reasons that carers are involved?

Key information:
Were carers involved before the new degree? (How established is involvement?)

Possible examples
- GSCC imperatives
- Government directives

5 Enabling processes
5.1 Recruitment and selection of carers

Key information:
Identifying partners:
Approaching partners:
Individuals or local organisations:
Identifying carers (individuals):

Possible examples
- Carers identified by staff from personal contacts
- Project worker developed links with local carers organisations

5.2 Orientation, training and support

Key information:
Skills and capabilities of carers:
Training and support programmes:
Induction for carers:
Pastoral support for carers:

Possible examples
- Carers escorted by support worker
- Carers meeting separately in dedicated carers’ group
- Carers attend teaching and learning training programme

5.3 Leadership and management

Key information:
Dedicated staff (employed by whom?):
Is there a carers’/users’ organisation?
How is it managed?

Possible examples
- Carers are employed as development workers within school
- An external organisation is commissioned to provide this role
- Role has been assigned to a member of staff in addition to normal workload

5.4 Resources

Key information:
Payment/expenses:
Other ways carers are paid (not money):
Are skilled support staff provided?

Possible examples
- A support worker arranges access to respite services funded by charities and other organisations
- Carers are hired as associate tutors
5.5 How are online resources used for the above, if at all?

Key information:

Use of online facilities:
Possible examples
• Carers are kept informed via web and email
• Carers’ stories are recorded and distributed over the web

6 Significant barriers (if any)

Key information:
What have been the barriers to it working well?
How have you overcome/addressed the challenges/barriers?
Have you come across any difference or difficulty working with carers and service users together?
Possible examples
• Resolving deference between carers and service users
• Dealing with reluctance from other staff
• Coping with limited resources

7 Future participation

7.1 Interest and willingness to be involved in a regional workshop

Key information:
Current links:
Perceived benefits:
Willingness to host?
Willingness to present case study as ‘good practice’?

7.2 Interest in using a web tool

Note: SCIE is exploring the development of a web-based networking facility to support carers and HEIs. This information will assist the development of a web tool.

Key information:
What would you like a website to offer?

8 Recommendations for further contact

Possible examples
• Local carers’ organisations
• Other professionals
Appendix 3: Survey guide: carers

Carers as Partners (CaPs), a SCIE-commissioned carers in social work education project

(This draft: 22 October 2008)

This guide is for interviews with carers involved in work including carers in social work education. This is a guide to aid the telephone interviews in the mapping phase of the project. It is essentially a set of subject headings/questions to aid the surveyor in getting data on all topics that have been identified as crucial to this project.

Brief notes and key advice for the interviewer

Method and style

• Where possible, carry out the interviews as a friendly and enquiring conversation.
• Where possible, make contact with interviewees to book a time to carry out the conversation. Advise the interviewee of information in the above steps at the time of booking.
• Introduce yourself and the project.
• Identify the project as: Carers as Partners (CaPs), a SCIE-commissioned project about carers in social work education.
• Ensure the person you are interviewing is appropriate for this enquiry (see ‘1 Who you are’).
• Reassure the interviewee that the duration of the interview will be limited (approximately one hour). (Give the option to continue should the interviewee wish to do so and the data is relevant to the enquiry.)
• State the purpose of this survey.

Purpose of enquiry

Project aims (agreed with SCIE)

1 To identify and report on the ways in which carers are involved in social work education
2 To identify the challenges encountered
3 To identify and promote the exchange of good practice
4 To explore how participation can be widened to include seldom-heard carers’ groups

Consent and confidentiality

Note: If recording the conversation, secure consent prior to beginning recording.

Inform the interviewee that the recording/notes of the conversation will only be used for the purpose of the study and will be disposed of at the end of the project.
Inform the interviewee that we will not identify respondents by name or higher education institution (HEI) without their specific consent. We will only be seeking this with regards to practice examples, where we will provide them with the draft text for approval prior to publication.

**Closure of interview**

Ensure the interviewee is aware of contact details for this project.

**Headings/questions**

<table>
<thead>
<tr>
<th>1</th>
<th>Who are you?</th>
<th>2</th>
<th>n/a</th>
<th>3</th>
<th>What do you do (with the university or college) regarding:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.1</td>
<td>Teaching?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.2</td>
<td>Assessment?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.3</td>
<td>Recruitment and selection?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.4</td>
<td>Programme management?</td>
</tr>
<tr>
<td>4</td>
<td>Why do you do this?</td>
<td>5</td>
<td>What enables you to do this?</td>
<td>6</td>
<td>Are there any significant barriers?</td>
</tr>
<tr>
<td>7</td>
<td>Would you like to do more (across England)?</td>
<td>8</td>
<td>Who else should we talk to?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Guidance notes**

1. **Who are you?**

   **Key information:**
   - Name:
   - Connection to university or college:
   - Which of the following difficulties would best describe the position of the person(s) you are caring for?

   - [ ] Older people
   - [ ] Mental health
   - [ ] Learning disability (adult)
   - [ ] Substance addiction
   - [ ] Physical and sensory disability
   - [ ] Children (with disability)

   *(For each section, continue overleaf if required...)*

2. **n/a**

3. **What do you do (with the university or college) ...**

   Please tell me about how you are involved in:

   3.1 **Teaching**
   - Design of module(s)
   - Delivery of teaching session(s)
   - Evaluation (monitoring and review)

   **Key information:**
   - Activity:
   - Frequency:
   - Noteworthy results from evaluation:
   - Development (resulting from evaluation):
   - How well established:
3.2 Assessment
• Design
• Delivery

Key information:
Contributing to a grade for the student or simply to provide formative feedback:
Acceptance by other colleagues?
Possible examples
• Carers in exam boards

3.3 Recruitment and selection
3.3.1 Interviewing individual applicants
• Design
• Delivery

3.3.2 Group interviews
• Design
• Delivery

Key information:
Contributing to selection or providing formative input:
Possible examples
• Carers help draw up candidate specification and suggest interview questions
• Carers are represented on the interview panels

3.4 Programme management

Key information:
Participation in programme (eg BA or MA) committees or boards:
Participation in course review or boards (eg specific modules):
Possible examples
• Carers attend senior management team meetings
• Carers attend planning meetings

4 Why do you do this?
How did you come to be involved?
And why do you continue?

Key information:
Nature of reward:
Part of a user/carer group in university?
Possible examples
• Personal satisfaction
• Social contact
• Payment

Some universities and colleges offer recognition of the skills and abilities of carers in the form of academic credits – would this be of interest to you?

5 What enables you to do this?
5.1 Getting involved in the first place

Key information:
Volunteering or being approached:
Connection to group(s):
Possible examples
• Carers identified by staff from personal contacts
• Project worker developed links with local carers organisations

5.2 Orientation, training and support
Key information:
Skills and capabilities:
Training and support programmes:
Induction for carers:
Pastoral support:
Possible examples
• Carers escorted by support worker
• Carers meeting separately in dedicated carers group
• Carers attend teaching and learning training programme

5.3 Leadership and management
Key information:
Dedicated staff (employed by whom?):
Is there a carers'/users’ organisation?
How is it managed?
Possible examples
• Carers are employed as development workers within school
• An external organisation is commissioned to provide this role
• Role has been assigned to a member of staff in addition to normal workload

5.4 Resources
Key information:
Payment/expenses:
Other ways carers are paid (not money):
Are skilled support staff provided?
Possible examples
• A support worker arranges access to respite services funded by charities and other organisations
• Carers are hired as associate tutors

5.5 Do you use online resources (the web) for this at all?
Key information:
Use of online facilities:
Possible examples
• Carers are kept informed via web and email
• Carers’ stories are recorded and distributed over the web
6 Are there any significant barriers?

*Key information:*
What have been the barriers to it working well?
How have you overcome/addressed the challenges/barriers?
Have you come across any difference or difficulty working with service users?

*Possible examples*
- Resolving deference between carers and service users
- Dealing with reluctance from other staff
- Coping with limited resources

7 Would you like to do more (across England)?
7.1 Interest and willingness to be involved in a regional workshop

*Key information:*
Current links:
Perceived benefits:
Willingness to present case study as 'good practice':

7.2 Interest in using a web tool

*Note: SCIE is exploring the development of a web-based networking facility to support carers and HEIs.*
This information will assist the development of a web tool.

*Key information:*
What would you like a website to offer?

8 Who else should we talk to?

*Possible examples*
- Local carers’ organisations
- Other professionals
Appendix 4: Call for information

Introduction and invitation to participate: Carers in Social Work Education project

(Draft: 24 September 2008)

Call for information about carers involved in social work education

The School of Social Work and Social Care at the University of Sussex has been commissioned by the Social Care Institute for Excellence (SCIE) to undertake a study of initiatives to engage carers in the education of social workers throughout England and to support the formation of a national forum. The project forms part of the second stage of a national project commissioned from SCIE by the Department of Health (DH) to develop a strategy to support participation of service users and carers in social work education.

The project will sample a number of social work degree programmes to report on innovations in carers’ participation and identify the challenges encountered. By working in partnership with Carers UK and The Princess Royal Trust for Carers, the project team will be seeking to identify and report on sites where there is known expertise and innovative practice. The project will also seek to promote exchange of good practice through regional and national consultation events, leading to the formation of a national forum.

The project is issuing a call for information on current or recent initiatives in engaging carers in social work education. If you have knowledge of a local project whose members may be interested to participate and share their experiences, please contact Associate Research Fellow: Andy Cheng (email: a.cheng@sussex.ac.uk).

Professors Suzy Braye and Imogen Taylor are leading the project, with Associate Research Fellow Andy Cheng as project manager, working to a steering group which includes representatives of Carers UK, The Princess Royal Trust for Carers, Crossroads Care and carers with experience of involvement in social work education. For more information please contact any member of the team:

Suzy Braye, 01273 876648, s.braye@sussex.ac.uk
Andy Cheng, 01273 876689, a.cheng@sussex.ac.uk
Imogen Taylor, 01273 872511, i.j.taylor@sussex.ac.uk
## Appendix 5: Regional cluster groups (RCGs): event schedule template

### Carers as Partners (CaPs) (in social work education)

<table>
<thead>
<tr>
<th>Start time</th>
<th>Duration</th>
<th>Details</th>
</tr>
</thead>
</table>
| 10.40      | 20 mins  | **Registration**  
*Opportunity to process expenses and payment claims forms* |
| 11.00      | 5 mins   | **Welcome**  
- Housekeeping notices  
- Permission to record  
- Meeting ground rules  
- What to expect today |
| 11.05      | 5 mins   | **Introduction 1: About this event**  
- Relevant and brief summary of the CaPs project  
- How participants’ contributions will be used |
| 11.10      | 10 mins  | **Icebreaker session**  
- In pairs  
- Ask your partner three questions:  
  - What is your favourite animal?  
  - What was the last television or radio programme you remember?  
  - What did you have for breakfast?  
- In turn, tell the whole group your partner’s answers to these questions  
Then (given the background of this project):  
- Who are you?  
- Why are you here?  
- What would you like to get from this event? |
| 11.20      | 5 mins   | **Introduction 2 – by participants** |
| 11.25      | 5 mins   | **About appreciative inquiry**  
This method must be handled with sensitivity and care. Commonly the method can fail if participants feel patronised or perceive they are being manipulated to support a view they do not subscribe to.  
When introducing this method, set up ground rules which provide:  
- clear invitation for honesty and openness  
- good recognition and validation for any negative comments *before* asking for discussion about ‘how things could have been done so as to have been successful’ and  
- clarity on how the input from participants will be used to improve circumstance of the topic(s) in discussion (including the timescale for this) |
<table>
<thead>
<tr>
<th>Time</th>
<th>Duration</th>
<th>Activity</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.30</td>
<td>90 mins</td>
<td>Two parallel workshops</td>
<td>Distribute participants roughly evenly across the three subjects (5-8 participants plus facilitator and clerk per workshop space/table)</td>
</tr>
</tbody>
</table>

**Workshop 1:** from your point of view, what are the features of effective and successful involvement of carers in social work education?

What are the best ways of accommodating work with service users and with carers in social work education?

Please consider:

- How carers are involved in:
  - teaching
  - assessment
  - recruitment and selection
  - programme management

- Future participation:
  - What you can do locally?
  - What can be done nationally (England wide)?

**Workshop 2:** from your point of view, what are the features of effective ways of engaging seldom-heard carers and enabling them to get involved?

What are the best ways of accommodating work with service users and with carers in social work education?

Please consider:

- What enables carers to be involved in:
  - recruitment and selection of carers
  - orientation, training and support
  - leadership and management of their involvement
  - the resources needed

- Future participation:
  - What you can do locally?
  - What can be done nationally (England wide)?

<table>
<thead>
<tr>
<th>Time</th>
<th>Duration</th>
<th>Activity</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.00</td>
<td>5 mins</td>
<td>SCIE web tool, part 1</td>
<td></td>
</tr>
<tr>
<td>13.05</td>
<td>35 mins</td>
<td>Lunch</td>
<td><em>Opportunity to process expenses and payment claims forms</em></td>
</tr>
<tr>
<td>13.40</td>
<td>10 mins</td>
<td>SCIE web tool, part 2</td>
<td>Feedback</td>
</tr>
<tr>
<td>13.50</td>
<td>25 mins</td>
<td>Whole group discussion</td>
<td>What do you think the priorities are for social work education?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>What (if anything) will you take away from today?</td>
</tr>
<tr>
<td>14.25</td>
<td>5 mins</td>
<td>Feedback forms</td>
<td></td>
</tr>
<tr>
<td>14.30</td>
<td></td>
<td>End</td>
<td><em>Opportunity to process expenses and payment claims forms</em></td>
</tr>
</tbody>
</table>
Appendix 6: List of organisations interviewed in the mapping phase

The Carers as Partners (CaPs) team would like to express our sincere gratitude to the people in these organisations for their contribution to this study.

<table>
<thead>
<tr>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>University of Birmingham</td>
</tr>
<tr>
<td>Bournemouth University</td>
</tr>
<tr>
<td>De Montfort University</td>
</tr>
<tr>
<td>London South Bank University</td>
</tr>
<tr>
<td>Northumbria University</td>
</tr>
<tr>
<td>University of Chichester</td>
</tr>
<tr>
<td>University of East London</td>
</tr>
<tr>
<td>University of Gloucestershire</td>
</tr>
<tr>
<td>University of Hertfordshire</td>
</tr>
<tr>
<td>University of Huddersfield</td>
</tr>
<tr>
<td>University of Kent</td>
</tr>
<tr>
<td>University of Northampton</td>
</tr>
<tr>
<td>University of Portsmouth</td>
</tr>
<tr>
<td>University of Salford</td>
</tr>
<tr>
<td>University of Sunderland</td>
</tr>
<tr>
<td>University of Sussex</td>
</tr>
<tr>
<td>University of Sussex and Brighton University</td>
</tr>
<tr>
<td>University of Teesside</td>
</tr>
<tr>
<td>University of Winchester</td>
</tr>
<tr>
<td>Anglia Ruskin University</td>
</tr>
<tr>
<td>Thames Valley &amp; Uxbridge Cares development manager</td>
</tr>
<tr>
<td>North Tyneside Carers Centre</td>
</tr>
<tr>
<td>FOCUS</td>
</tr>
<tr>
<td>Medway Carers Centre</td>
</tr>
<tr>
<td>Service user and carer consultative group</td>
</tr>
<tr>
<td>Carers in Partnership</td>
</tr>
<tr>
<td>Carer and activist</td>
</tr>
<tr>
<td>Carer</td>
</tr>
<tr>
<td>Carers and Users Partnership</td>
</tr>
<tr>
<td>Carer</td>
</tr>
<tr>
<td>Coventry Carers Centre</td>
</tr>
</tbody>
</table>
Appendix 7: Summary of feedback sheets from all three regional cluster groups (RCGs)

Carers as Partners (CaPs) (in social work education)

<table>
<thead>
<tr>
<th>Number of people attending</th>
<th>South West</th>
<th>West Midlands</th>
<th>North West</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delegates</td>
<td>5</td>
<td>19</td>
<td>21</td>
<td>45</td>
</tr>
<tr>
<td>CaPs and local support team members</td>
<td>3</td>
<td>4</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>23</td>
<td>27</td>
<td>58</td>
</tr>
<tr>
<td>Form returned/number of delegates</td>
<td>5/5</td>
<td>15/19</td>
<td>19/21</td>
<td>39/45</td>
</tr>
</tbody>
</table>

1 How delegates described themselves (multiple descriptions allowed)

<table>
<thead>
<tr>
<th></th>
<th>South West</th>
<th>West Midlands</th>
<th>North West</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer/former carer</td>
<td>4</td>
<td>12</td>
<td>15</td>
<td>31</td>
</tr>
<tr>
<td>University/college staff</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Carers’ centre staff</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other (specified as):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skills for Care</td>
<td>1</td>
<td>–</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td>service user</td>
<td>–</td>
<td>2</td>
<td>–</td>
<td>2</td>
</tr>
<tr>
<td>carer and service user-led organisation</td>
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2 What delegates wanted to get from the day’s event

Networking, making contacts and sharing ideas:

- Awareness of others’ viewpoints (and) how national debate on service user/carer is progressing
- Opportunity to meet carers and hear their views etc – how this might impact on regular work
- Clearer picture of carers – partner’s role national and where improvements could happen
- A lot of motivation and look forward to seeing the end of report of today’s event
- Involvement, ideas, feedback, networking, future opportunities
- An overview of a range of carers’ ideas and perceptions
- Networking
- To hear from others and be part of developing social work education
- Good ideas to take back with me and present to the students
- Ideas from other organisations and other carers
- Shared knowledge/experiences of other carers/universities involved in social work education
- Networking
- Information
• Ideas from other individuals/groups involved with universities
• Learn from other people’s experiences
• More information, ideas and personal contacts
• Learning more about developments on carers’ involvement and contribute what I could from our programme’s experience

Finding out about social work education (and carers involvement in this):

• Greater awareness of how complex it is involving carers and users within social work education and real hope for the future because of the enthusiasm, caring and organised approach
• To get a better understanding of the role carers play in diverse educational institutions
• Better insight into what contribution carer involvement within the university (is made)
• Knowledge about the programme – carers as partners
• More understanding of other university programmes and involvement in social work degrees
• Information on what is happening regarding carer involvement in other parts of the region
• How the ‘dark side’ is trained, that change is too rigid due to costs, a lack of direct ‘carer’ contact
• Information about carer involvement in social work education
• Information/knowledge of anything to do with carers and their caring role
• Information
• Learned a lot from today regarding social workers working with each other in the future

Recognition and being valued:

• Listen to and give ideas to improve carer involvement in social work degree
• Satisfaction from participation in intellectual, meaningful discussion and having a chance to influence the future
• It is good to know there are more people who wish to listen
• The knowledge that our views as carers would be reflected in student training
• Being listened to

Exploring the distinction between services users and carers:

• Discrete views of carers regarding social work education; separate from users
• Views; not always many fora to do that
• More awareness of differences between carers and service users, with carers being a distinct group

Exploring how to get involved:

• How to become more involved in my locality – extend networking opportunities/contacts
• An understanding of what’s involved and how I may become involved and if the project would be relevant
• Get more involved

No prior goal(s) for attending:

• No preconceived ideas, but hopefully some of my points will be taken on board
• Didn’t know
• Unsure

Other:

• Everything that we discussed
• Hope for improvement

3 Number of delegates thinking they got what they wanted

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<th>South West</th>
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Other comments:

• N/A
• Very much so
• I was unsure what to expect and hope I was able to communicate in a helpful way
• I feel really valued today and it was a great pleasure to meet you all and be involved
• I think I got a good picture of where we are as carers in terms of the work we do and how valued we are
• Views from carers working with HEIs [higher education institutions]
• Ideas not considered before, eg carer involvement in staff appointments
• Would like more time
• Hopefully
• And more
• [Got] more knowledge and information
• I shall know in a few days
• Didn't have enough info on aims of the day to evaluate this
• I learnt that the ‘core’ element was lacking, the actual provision of care
• Now aware that local universities are involved and opportunity to explore further is there
• Not very good at talking in groups but managed to make a few points
• I would have liked to have seen more university staff involved with service users/carers
• Very few people here with experience of involvement – some appeared to be here to resolve strong long-term problems with their social workers
• The course was very informative and I now have a greater understanding of this project
• Staff and review (?) were good. Too early to comment
• Couldn’t, as already could not attend due to a meeting at work, until 1.30 then had
meeting, went on longer and no tram from the city centre!!
• It was a very informative, cozy day with lots of things/topics to churn over. Very
interesting

4 What (if anything) delegates thought would have made this event better

More time:

• If we could have had two days it would have been great
• Perhaps a bit longer or another day
• More time for discussion
• Maybe more time
• A longer time for debate
• More time
• Longer time
• More time
• More time, but appreciated shortness of day, as fits with carers’ ‘caring’ role
• More time
• More time of course
• More time
• More time

Wider variety of attendees:

• I would have liked to have seen more university staff involved with service users/
carers
• Perhaps more people invited from universities
• Inclusion of other groups eg the University of Manchester Department of
Psychology has an experienced service user and carers group
• Maybe ask the six delegates
• And more people
• I guess would have been good to have carers from wider range of universities

Better information prior to event:

• To know beforehand that the topic was mainly about social work
• And more pre-meeting information
• Greater clarity about purpose of the event beforehand
• Better information beforehand
• Advance information about what was expected of me
• Advanced information
• More preliminary information

Other:

• Far more dialogue and ‘open’ debate
• Less content, more exchange of information
• From personal perspective knowledge of what’s going on with other programmes (I only know about the University of Birmingham, involved with them)
• Still slightly confused about web tool
• Cannot say at this time
• N/A
• Not sure, well led meeting
• Much better perspective overall picture
• I felt there was a lot of focus on administrative issues rather than the practical teaching/caring practicalities

5 Number of delegates who thought this type of group should continue to meet in the future

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Other comments:

• Through our regional group, please!!
• Because this type of group generate new ideas for future involvement of carers
• Useful for carers and HEIs
• Very much so
• Useful to hear ways carers are involved in the different universities; creative ways
• Perhaps develop a group on the Wirral
• Needs to be targeted
• The meeting up with each other gives us hope for the future
• Pool ideas/developments

5.1 Number of delegates who would like to be contacted about coming to future meetings

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6 What actions were delegates thinking of doing as a result of the day’s event?

Carers:

• Get involved with training students on BME [black and minority ethnic] and DRE [delivering race equality]
• Contact local universities to explore possibilities of becoming involved
• Getting involved in social care training even if only in a small way (priorities and time permitting)
• Word of mouth to other carers and good points into action
• Continuing involvement at UCLAN
• Build an involvement with university
• Speaking to more carers about carer participation and encourage them to become involved
• I would like to meet up with social workers to discuss the future for carers and how we can help each other
• I am looking forward to being involved with you again and to speak to social workers
• Enlightening others (ie, other carers to want to be involved in these events)
• Look at carer involvement in preparation of student placement
• Continuing to try to make system better for future carers
• Making other carers aware of the involvement of carers in social work education
• I will continue to attend the Plymouth User and Carers Social Work meeting
• I will certainly be checking the ‘web tool’ development
• Trying to access Carers UK website, The Princess Royal Trust etc to exchange ideas views etc
• Would like to be part of ‘working party’ group – writing about experiences of caring for physically disabled partner
• Come to more events like this one
• To follow you up!
• If a door opens – walk through it!
• To know more about ADHD [attention-deficit hyperactivity disorder] carers to have more support so that people are more aware of ADHD
• Need to reflect on this point
• Will have to think and ponder on that question
• I don’t feel I am in a position to take any actions

HEI:

• Feedback to my coordinator
• Feedback to SU [service user]/carer advisory group
• Widening network of service user and carers involved
• Trying to promote more carer and service user involvement in practice learning – this is an area needing more development on our programme (as all areas of involvement)
• Thoughts on carers’ input on staff appointments
• More commitment/involvement with seldom-heard groups – young carers
• Evaluating much of our picture
• Passing info on to the SW [social work] RAG group
• Feeding back to university SU/carers and involve their comments

Carers’ centre:

• Wait to hear more about how we can involve the rest of our membership

SU/carers’ group

• Introduce carer and service user design module
• Collate information and notes and disseminate to carers unable to attend
• Sending Andy a copy of carers in partnership’s helpline professional learn from carers group guidance paper re engagement with universities etc
• Review own practice in response to knowledge about others carers’ involvement
Other:

- Fight harder to keep our group going! Publicise it more

6.1 Other comments

- Excellent day and good opportunity for sharing ideas
- Please ensure all contributors are told when the report comes out
- Improvement is info sharing and active interactive web page
The Carers as Partners (CaPs) team would like to express our sincere gratitude to these people for their contribution to this study.

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Carers as Partners (CaPs) in social work education

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