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## Evaluation of the National Carers Organisations' Carer Training Initiative

The independent evaluation of the National Carers Organisations Carer Training Initiative was carried out under the auspices of Glasgow Caledonian University in collaboration with the University of Dundee. This section of the report describes the evaluation. It begins with the overall evaluation methodology. Then the results of the evaluation for each project (Black and Minority Ethnic Carers and Rural Carers) will be presented separately. Following these separate results, an overall perspective will be given followed by a discussion and recommendations.

### Methodology

The aim of the National Carers Organisations' Carer Training initiative (hereafter called the NCO Project) was to provide opportunities for unpaid carers from Black and Minority Ethnic (BME) communities and from the Highlands to take part in learning and personal development and to continue their role safely. The grant further outlined specific objectives which were to:

- support and improve carers emotional, physical health and wellbeing
- support and develop carers skills and knowledge
- provide opportunities to enable carers to have “an ordinary life” including the opportunity to take part in education and lifelong learning and learn skills to enter or return to employment.
- provide a sound knowledge and information base to form a comprehensive strategy for carers learning and development.

In order to evaluate the effectiveness of the NCO Project it is necessary to examine if the NCO Project met the objectives above, and if so, identify how they were achieved. This would necessarily include outcome evaluation (e.g. what was the impact of the Project on carers' lives and/or what were the benefits to carers) as well as some process evaluation (e.g. who benefitted from the Project, what barriers did the Project come across and what made the Project successful or unsuccessful). With such a broad evaluation mandate a multi-method evaluation design was required. The evaluation received research ethics approval from Glasgow Caledonian University.

***Pre-test post-test design*** – Course participants were asked to complete a questionnaire prior to taking their first training course and again after they finished their training. The post-test questionnaires were to be administered approximately 6 weeks after the final training. However, the time ranged from shortly after the final course to several months. The questionnaire was translated into Chinese and Urdu for those participants whose first language was not English.

The questionnaire used a continuous rating scale format of 17 different items. Each item contained statements worded negatively or positively at each end of the rating scale which ran from -3 to +3. The areas measured included:

- Feelings about being a carer
- Confidence in relation to being a carer

- Ability to manage the caring situation
- Physical and emotional health
- Feelings of stress
- Time for self
- Feelings of isolation
- Support for self as a carer
- Communication with professionals
- Working with professionals
- Financial situation
- Knowledge in relation to the course taken
- Skills in relation to the course taken
- Quality of care provided
- Difference the course made to caring situation
- Attention to culture

In addition, two open ended questions were included that asked carers to explain any of their answers or to tell us anything they wished about their experience of being a carer. Finally, demographic information was also collected. The instrument was adapted from a carers questionnaire developed by the Kings Fund and it has been used with a similar evaluation occurring in the Lothians (PRTC, 2006). The questionnaire allows for quantitative evaluation of some of the key NCO Project objectives regarding carers' emotional health, physical health and wellbeing and developing carers' skills and knowledge. The data were analysed using SPSS 16. Where appropriate paired sample t-tests and unpaired *t*-tests were used to test for differences on the questions before and after the training. Descriptive statistics were used to summarise demographic data.

An additional training evaluation questionnaire was used in the BME projects. This pre-post training questionnaire consisted of five questions asking participants to rate their knowledge and skills that were taught in the training sessions using a 5-point continuous rating scale. The end points of the scale were "I really need help" and "I am confident I know about this." Three other questions asked about satisfaction with training methods. The data were analysed using SPSS 16. Where appropriate paired sample t-tests were used to test for differences on the questions before and after the training.

**Focus groups** – Questionnaires are an excellent way to capture a large amount of data and when the questions yield quantitative data they can be extremely useful in measuring outcomes. However, one of their drawbacks is that they can lack depth or do not facilitate exploration and explanation required to answer some evaluation questions. As such, focus groups were designed to be used as part of the evaluation to examine outcomes and process variables of interest to the evaluation. This included some areas also addressed in the questionnaire but additionally gave participants the opportunity to describe potential benefits of the training that were not part of the questionnaire. Focus groups also explored process variables such as training methods and attention to culture. Finally they also allowed participants to identify next steps for them as carers.

Face to face focus groups were held with carers from Black and Minority Ethnic groups in Dundee, Edinburgh, and Glasgow. Translators were used for the Chinese carers and the Asian Carers. One group of Black carers was conducted in English; however a representative from the host BME organisation was present in the focus group at the carers' request. Focus groups with rural carers were held in Dingwall and Thurso. In addition, three telephone focus groups were held with carers from other parts of the Highlands. The interviews were recorded and analysed using thematic content analysis facilitated by N-Vivo 8.

***Interviews with trainers, outreach workers and interpreters*** – When including process variables in an evaluation it is helpful to gather the views of people who are intimately involved with the process, in this case people delivering the training or providing the interpretation service. These key stakeholders will have an important perspective on how the training was delivered and how it was received. As such a series of individual interviews and focus groups was held with trainers, outreach workers and interpreters, and these interviews addressed issues such as strengths and weaknesses of the training, barriers to providing the training, any benefits they observed, and changes they would make if doing the training again. These interviews were analysed using thematic content analysis facilitated by Nivo-8.

***Interviews with Project Leads*** – Finally interviews with Project Leads were held in order to get a strategic overview of the entire project and their perspectives on the initial data analyses, barriers and difficulties they experienced, lessons they learned, and other thoughts about the strengths and limitations of the projects. Again these interviews were analysed using thematic content analysis.

The multiple sources of data allowed for a triangulation of findings during the analysis. Cross cutting themes were identified in the focus groups and interviews with the carers, trainers, interpreters and Project Leads. In addition, explanations for some of the quantitative findings were explored.

## Results for the Black and Minority Ethnic Training Project

As indicated elsewhere in the report, the pilot project targeting carers from Black and Minority Ethnic (BME) communities was run under the auspices of MECOPP. Working in partnership with existing BME organisations as well as through their own client base, MECOPP facilitated a range of training sessions for Chinese, South Asian and Black carers in Dundee, Edinburgh, Glasgow and Perth. The courses included Moving and Handling, Emergency First Aid, Incontinence Management, Looking after Yourself, Challenging Behaviours, and Arthritis Care. In addition, they provided training to professionals on working with interpreters.

### Participants in the Evaluation

A total of 34 carers completed the NCO evaluation questionnaire. In addition a total of 32 carers completed a pre-post training evaluation form that MECOPP developed independently. The results of each will be presented.

Of the 34 participants completing the NCO evaluation questionnaire 35% came from Dundee courses, 47% came from the Edinburgh Courses and 18% came from the Perth courses. No returns came from the Glasgow courses. The majority of the carers were over 50 years of age (see figure 1) and as would be expected the vast majority (91%) were women. Sixty-five percent of those completing the questionnaire were Chinese (n=22) and 35% were Asian (n=12). Nearly 40% of the carers were caring for a parent (see figure 2). As the carers and the cared for were generally older people, it is not surprising that the illnesses or disabilities of the people being cared for were overwhelmingly illnesses associated with ageing (see table 1). The carers had been providing care for an average of 8.8 years (s.d.= 7.9) with a range from 1 year to 30 years. They provided care for an average of 10.2 (s.d.=7.8) hours per day with a range from 3 hours to 24 hours. Only 17% (n=6) of the carers indicated that they had ever received any carers' training previously and almost all of the carers (83%) found out about the training offered as part of this project through BME community organisations or BME carer outreach workers.

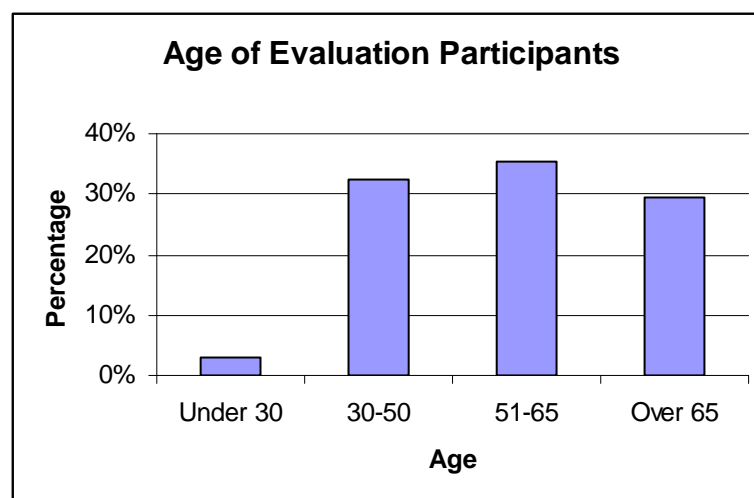


Figure 1: Age of Participants

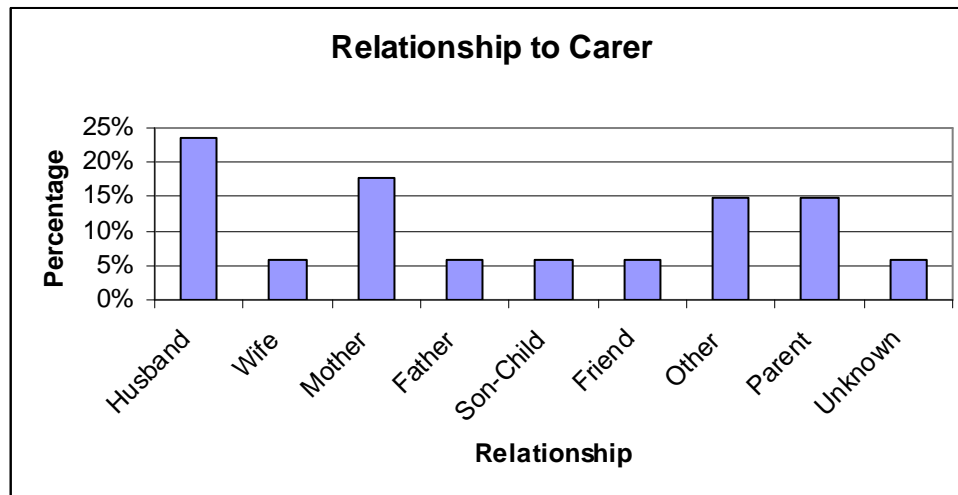


Figure 2: Relationship to Carer

### Pre-test Post-test Carers Questionnaires

A total of 24 participants answered both the pre and post carers questionnaire. However, not all questions were answered at both points in time. As such, some of the questions had less than 24 pairs for comparisons. The scores before and after the training courses were compared using a paired *t*-test. The results of the analysis are summarised in table 2. For 16 of the 17 questions a significant positive change was found from pre to post-test. One question concerning culture was not analysed as only 3 people completed the question at both time periods. The positive results may indicate that carers' knowledge, skills and well being improved from pre-training to post training. However, these results must be viewed cautiously as there may have been threats to internal validity which will be discussed later.

Illness/Disability	Percentage	N
Frail and weak	18%	6
Unknown	12%	4
Dementia	12%	4
Multiple Illnesses	12%	4
Stroke	9%	3
Autism	6%	2
Cancer	6%	2
Arthritis	3%	1
Diabetes	3%	1
Disability	3%	1
Down's Syndrome	3%	1
Gout	3%	1
Heart Disease	3%	1
Kidney Disease	3%	1
Mental Health Problems	3%	1
Wheelchair bound	3%	1

Questionnaire Item	Mean Change	Std. Dev.	t-value	df	p-value
I am often very negative/positive about my caring situation	-1.456	1.14	-6.26	23	0.00*
I do not/do feel very confident in my role as a carer	-1.67	1.13	-7.23	23	0.00*
I do not/do manage my caring responsibilities well	-1.25	0.79	-7.71	23	0.00*
My health is seriously affected by my caring situation/My caring situation has no effect on my health	-1.74	1.14	-7.34	22	0.00*
My emotional health is seriously affected by my caring situation/My caring situation has had no effect on my emotional health	-1.74	1.18	-7.09	22	0.00*
I frequently feel/rarely get stressed by my caring	-1.48	1.16	-6.10	22	0.00*
There is nothing in my life except caring/I have plenty of other interests beyond caring	-1.91	1.34	-6.67	21	0.00*
I feel/rarely feel isolated as a carer	-1.42	0.88	-7.88	23	0.00*
I do not feel/usually feel supported in my caring role	-1.46	0.72	-9.91	23	0.00*
I am not/I am confident talking to care professionals about what I need	-2.26	1.29	-8.43	22	0.00*
I feel I am unable/am able to work with care professionals as a key partner	-1.78	1.09	-7.88	22	0.00*
My financial situation has been greatly affected/has been unaffected by my caring situation	-1.19	1.05	-4.54	15	0.00*
I know little about course topic/I feel knowledgeable about course topic	-1.91	1.23	-7.28	21	0.00*
I feel very unskilled/skilled in relation to the course I am undertaking	-1.67	1.20	-6.78	23	0.00*
I have a lot of concerns about the quality of care I provide/The quality of care I provide is to a high standard	-1.909	0.92	-9.72	21	0.00*
This course made little difference for me as a carer/The course had a significant impact on my ability to care	-1.143	0.66	-6.45	13	0.00*

The training evaluation questionnaire had similarly positive results. This questionnaire consisted of 5 questions concerning knowledge, techniques and confidence in areas delivered in the training. There was a significant positive change from pre-test to post-test on all questions for all three training courses. These results are summarised in Table 3 and figure 3.

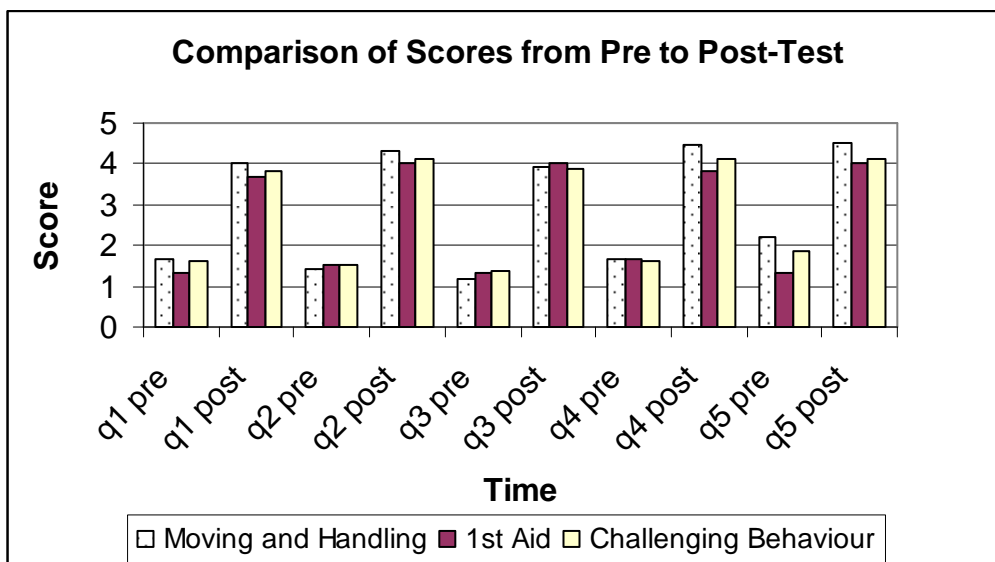


Figure 3

<b>Table 3</b>			
<b>Training Evaluation Results</b>			
<b>Moving and Handling Course</b>			
	t	df	p-value
I am familiar with different techniques that can be used for moving and handling the person I care for	-7.40	15.00	0.00*
I am aware of the methods I can use in order to make sure I am not uncomfortable and do not cause myself physical harm	- 14.26	15.00	0.00*
I am aware of and confident of the correct use of hoists and other suitable aids to moving somebody	- 11.82	15.00	0.00*
I am confident in my own ability to make use of the techniques which are suitable for moving and handling	- 12.58	14.00	0.00*
I am confident that I would be able to get the help required if I were unable to move the person I care for	-7.10	15.00	0.00*
<b>Emergency First Aid Course</b>			
	t	df	p-value
I know resuscitation techniques and am confident that I would be able to use them	-2.91	5.00	0.02*
I know what to do to stop bleeding and would be able to apply the techniques	-5.00	5.00	0.00*
I am confident of what I would do if the person I care for were to have a heart attack	-4.34	5.00	0.00*
I know what to do if somebody is choking and am confident in how to apply this technique	-3.99	5.00	0.01*
I understand what I would do if somebody has been burned or bruised and am confident I would apply the right technique	-4.78	5.00	0.01*
<b>Managing Challenging Behaviour Course</b>			
	t	df	p-value
I am familiar with the different techniques that can be used to manage challenging behaviour	-7.58	9.00	0.00*
I am aware of the relevant organisations which can provide support	-6.13	9.00	0.00*
I understand how to cope with the stresses and pressures which occur within my caring role	-6.71	9.00	0.00*
I am confident in my ability to make use of techniques which are suitable for managing challenging behaviour	-8.82	9.00	0.00*
I am confident that I could call on the appropriate supports as required within my caring role	-6.00	9.00	0.00*

### Focus groups with Carers

As indicated earlier, face to face focus groups were held with carers from Black and Minority Ethnic groups in Dundee, Edinburgh, and Glasgow. Translators were used for the Chinese carers and the Asian Carers. One group of Black carers was conducted in English, however a representative from the host BME organisation was present in the focus group at the carers' request. A total of 55 carers from Black and Minority Ethnic backgrounds participated in the five focus groups. The focus groups were recorded and analysed using thematic content analysis. The questions on the interview schedule served as the initial thematic analytical framework. In addition,

the analysis allowed for themes to emerge from the conversations participants engaged in with the focus group leaders as well as amongst themselves.

### Course Content

In each of the focus groups the participants were able to describe the courses they attended. For example, the Asian carers in Edinburgh discussed the content of the Arthritis Care course in detail and discussed some of the changes they had made in their lives as a result of the training (e.g. exercises, change in diet, treatments). This training was focused on caring for their own arthritis as they all were suffering from the condition and it impacted on their ability to care. They were clear that they needed to care for themselves so that they could continue caring. The Chinese carers in Dundee spoke at great length about the content of their moving and handling course and how they now know how to move without hurting themselves.

When asked if the course contents covered what they thought they should the overwhelming majority of the carers said yes. They also discussed other things they would have liked to see in the courses. For example, the Managing Arthritis group indicated that they would have liked to have more information on aids and adaptation as well as additional information about resources. The carers from the Managing Difficult Behaviour focus group would have liked more practical help and demonstrations. However, many of the carers stated that they did not know what to expect from the course as they were not used to coming to training. This was especially true in the Chinese carers group in Dundee. They reported being very pleased with the content and would be “very happy” to have more courses.

The course content was also deemed to be relevant by the carers

### How the courses were delivered

The focus group participants were extremely positive about the courses and how they were delivered. Any criticism or negative critique was veiled. However, it was clear that each of the focus groups described their preference for active learning. Some of the courses were primarily practical, with demonstration of skills and then practice. Others had more of a “theoretical” or talking component. Participants preferred the more active courses. As many of the carers were not literate in English nor in their first language, it would make sense that active learning was preferred. Visual aids would also have been warmly received by many of the participants. This was especially salient for the Chinese carers in Edinburgh who participated in the continence management course.

The Asian courses did not have a professional interpreter, and although the participants were very grateful for the translation provided by project staff, they felt it would have been better to have translators. There were also some feelings that the courses could have been longer as they were full of content.

### Cultural Issues

On one hand, focus group participants downplayed the importance of culture saying things such as arthritis is not just an Asian issue or that incontinence happens to

everyone not just Chinese people. Others felt that moving and handling techniques are the same regardless of what culture you come from. On the other hand, a great deal of the data suggests that paying attention to culture and overcoming cultural barriers were incredibly important to the success of the projects. For example, carers described how isolated they can become due to language barriers they faced. In some ways they are at double jeopardy for isolation...first because of being a carer, second because of language/cultural barriers. Asian carers described how inappropriate it would be for a male to deliver some hands on aspects of first aid or moving or handling. All the groups whose first language was not English described the importance of having a translator at the training events and/or having materials in pictures or in their own language.

Other cultural issues emerged in relation to the outreach efforts required to engage with carers from Black and Minority Ethnic communities. The carers described the importance of organisations such as MECOPP, the Chinese Community Centre, Ethnic Enable or the outreach workers from carers' organisations. Without the engagement efforts of these bi-cultural "ambassadors" or liaisons many of the carers would not have been able to participate in the training. Outreach efforts were described frequently by the carers as being the reason they were willing and able to come. As there were trusted relationships with these individuals and the organisations for which they work, the carers engaged with the project. In addition, the venues for most of the training events were held in local communities that the carers were familiar with and comfortable going to (e.g. the Chinese Community Centre). Two exceptions occurred. Day 2 of the Moving and Handling Course in Dundee was held in a training venue outwith the Chinese community. Focus group participants indicated that they would have been reluctant to attend if both days were held at this second venue. As Day 1 occurred on their home turf and they trusted the trainers they were able to attend outwith their comfort zone. Their community outreach worker was still necessary to help them attend at this unfamiliar place. The second exception occurred at the Incontinence Management training in Edinburgh. Focus group participants were mixed about this new venue. Though it was a nice venue many of them found it difficult and uncomfortable to attend.

### Benefits derived from Attending the Courses

*Provide Better Care* - In all the focus groups, participants described how they were able to take better care of the cared for person. For example, the Moving and Handling participants described how they were able to help their loved one negotiate stairs or in and out of bed safely. Even the Incontinence Management and Managing Arthritis courses which were designed more for dealing with these problems within the carer and not cared for, still had benefits for the cared for person. For example, the women in the Chinese Incontinence Management course described how they had resources now to better care for the toileting needs of the person they were caring for. They also felt better able to care as they were better managing their own incontinence. The Asian Managing Arthritis course participants were providing more nutritious and healthy food for the person they cared for as a result of their training.

*Increased Knowledge and Skill* - The feeling that carers could take better care was underpinned by a reported increase in knowledge and skill. In the Moving and Handling example given before, the Chinese carers described how their knowledge

in safe moving techniques, available resources, and needed adaptations increased. In addition, the training allowed them to put some of this new knowledge into practice and develop their skills. In the focus group some of the carers described how they were putting that new knowledge and skill into practice at home, and also discussed some of the difficulties they were having as they were implementing the new skill. The Asian Emergency First Aid course increased the participants' knowledge, but also had wider benefits as they reported that they were sharing their new knowledge with family and friends. One carer commented that prior to taking the course all she knew how to do in an emergency was dial 999 and scream. Now she feels she would know how to help the cared for person until emergency medical personnel arrived. She reported this gave her peace of mind and increased confidence. Mothers from the Managing Difficult Behaviour course indicated that they had more ways of dealing with some of the problematic behaviours their child engages in.

*Mutual Aid and Support* - The carers reported that a benefit of the training that went beyond the actual content of the courses was the mutual aid that occurred among the carers. Many of the carers felt isolated and unsupported prior to the training, and the courses provided the opportunity to receive support and a sense of not being the only one. In addition, the carers reported learning a lot for other carers as well. Being able to hear that other carers had similar difficulties and that some had found ways of dealing with the difficulties provided hope as well as practical advice.

*Access to Other Resources* - In each of the focus groups there were numerous stories of how the training courses provided referrals to or advice on how to access other needed services or resources. For example, the women in the Incontinence Management course laughed when they said that they all left the training with a piece of paper with the words "Tena Lady" written in English so they could show the chemist what they wanted. They did not know that such a product existed. The Chinese Moving and Handling group received many referrals to access aids and adaptations to help.

*Take Better Care of Selves* - Carers also reported taking better care of themselves after attending the training. For example, the participants in the Chinese Moving and Handling described how the emphasis of the course was how to safely move so that you did not hurt yourself. The carers described how they were taking that advice on board and some of the aches and pains had started to go away. The Managing Arthritis participants discussed how they were doing gentle exercises and eating a better diet subsequent to the training.

### Next Steps Identified by Carers

According to the participants in each of the focus groups, there has been limited opportunity for training and they are hungry for more training courses. The Chinese carers in Dundee were most emphatic about this as they repeated "More Courses, More Courses!" When asked what type of courses, these Chinese carers indicated that it did not matter...just any course related to caring. When pushed a little they were able to indicate courses similar to the other BME focus groups. These included courses on health condition specific topics, health and well being, nutrition and healthy cooking, pampering and respite. However, the carers would be appreciative

of any courses that the professionals thought they needed, especially practical courses.

### Information for Policy Makers or Service Providers

Focus group participants were asked to indicate what they would like policy makers and service providers to know about what it is like to be a carer from a Black Minority Ethnic community. They indicated quite clearly that language is a real barrier to them in their caring role. More courses that are suitable for them are required. In addition, more translation services are required so that they can access information, training, the services they need timeously. They also indicated that better treatment for the people they care for would make their lives better as carers. In addition, they felt it was important to have more people employed as outreach workers.

### **Interviews with trainers, community worker, translators and course organisers**

A focus group and interviews were held with the trainers, the translator, community workers and course organisers. These interviews focused on the same areas as the focus groups with carers but from the professionals' points of view. In addition this group of professional respondents were asked about barriers they faced in developing, designing or running the project. They were also asked specifically about any lessons they learned along the way. As the numbers of each group are small the results are described together to protect the confidentiality of the respondents.

### Barriers

This group of respondents faced several barriers during the course of the project. Time constraints were consistently voiced by the respondents. The respondents stated that the provision of services for BME carers is not robust at this point in time and a great deal of preparatory work is required to develop the networks, trainers, and outreach to marginalised and sometimes hidden communities. The short term nature of the pilot project meant that these processes were rushed and the developmental work required for what is in essence community organisation was given short shrift. Added to this, the original Project Lead left mid-way through the project. Two staff members took joint responsibility for the project but had less time in which to do the work. This added pressure to the already tight time scales.

These time constraints could also be felt at the individual course level. It was reported that once training priorities were identified, trainers needed to be identified, courses developed and delivered with appropriate supports. The trainers felt that they could have done even more if they had more preparation and planning time. If community outreach workers had more time they could have done more preparatory work with BME carers to help recruit and prepare the carers for the training. Within the delivery of each course time constraints were also felt. Because there were no trainers who spoke the language of the Asian or Chinese carers interpretation was necessary. Interpretation naturally is time consuming and as such the already packed curricula became even more difficult to deliver in the time allowed.

Other barriers identified included political issues and organisational/environmental challenges. Evidence for difficulties in working across boundaries was found. Though

for most projects the partners found a way to be sensitive to the work of other existing organisations and to work through differences of opinion. Different organisations also had different priority levels for BME carers. Working through these potential barriers was very time consuming and added to the time pressures identified earlier. Organisational challenges included changing staff at various partner organisations, differing relationships across partners, under resourced partners. These challenges are “typical” difficulties for organisations, but when forming partnerships they can have a negative impact on developments.

### Benefits to Carers

Several benefits were identified by these respondents – some of them planned and hoped for while others were unexpected. For example, they reported that carers gained a great deal of information that they needed. It is well known that carers, in general, struggle to get the information that they need from health and social care professionals (Kelly, 2006). For carers from BME communities, this struggle is even more difficult due to language and cultural barriers. An unexpected and related benefit was that these respondents were able to give examples of how carers who attended training events cascaded the learned information out to other BME carers who were not part of the training. Though measuring community impact was beyond the scope of this current evaluation, this anecdotal information is important.

The carers learned about supports and services that are available but that they were not receiving. Trainers described providing a lot of information at the training events about resources, aids, adaptations, benefits, organisations and services that would help the carers and to which they were entitled. The community workers indicated that carers also contacted them post training to follow up on some of these supports. Trainers also sent additional materials after the training event. According to the professional staff, these carers had an even greater dearth of information than carers from majority cultural groups. In some ways the trainers were shocked at this dearth, but as experienced and knowledgeable professionals, they were able to quickly and flexibly adapt the session to provide the needed information. An unexpected benefit was that the community workers who also participated in the training events learned a great deal of information about the carers they had been working with for a while. They did not know all the difficulties that the carers were experiencing, but the training courses brought these out in the open and follow up work has been possible.

This group of respondents also indicated that mutual aid and social support were important benefits of the training. They indicated that during the training courses carers were sharing and learning from each other. They reported that carers found the sharing and social aspect very important

This group of professionals reported that the carers appeared to value every second of the training. This group of carers has received so little that these courses were greatly appreciated especially since even basic information provided was new. As one person pointed out, one of the people being cared for could not come downstairs, and now their carer can get them downstairs. Another person who was having to walk on his knees and was getting terrible sores is now getting around pain free. Another carer who was hurting her back is now taking care of herself. Just providing these carers with basic information about resources, aids and adaptations,

and simple moving and handling techniques has made a considerable difference. These carers have not had anything and now the courses have given them access to information about rights and resources, showed them how to live and better care for themselves, and showed them what is possible.

### Cultural Issues

This group of respondents indicated that carers from BME communities face the same kinds of problems that all carers face. However, they also face additional difficulties and challenges such as language barriers and/or unresponsive services. Though most health conditions are not culturally specific, the ways in which people express their condition, deal with any associated shame, access services and supports can be different. Strategies for overcoming these additional challenges and providing culturally appropriate training were seen as important. As such, issues such as language, culturally appropriate food, cultural gender issues, accessible and familiar training venues were attended to.

These respondents indicated that it was vitally important to work in partnership with existing and recognised cultural organisations or cultural outreach workers. The outreach workers played a vital role in working with members of the different BME communities in order to get them to attend the courses.

Principles of adult education suggest that adults learn best through active and participatory learning (Merriam & Caffarella, 1991). The knowledge that learners bring is recognised and is used as a starting place for educational activities. According to the trainers, course organisers, and outreach workers, these principles are especially relevant for these carers. Many of the carers are not literate in English or their mother tongue and they are not used to formal education or training situations. As language was also an issue for most of these carers, verbal training was also not as helpful as practical and hands on training. The Chinese Moving and Handling course really embraced this approach and was perhaps the most successful course. Here the trainers were supported by an excellent translator who was also familiar with health and social care issues, the outreach worker and the Project lead. Rather than provide the theory of moving and handling, the Project Lead encouraged the trainer to start where the carers were and find out what were their particular challenges to moving and handling. This on the spot and time consuming needs assessment paid out dividends as the rest of the training was tailor made to meet the needs of the carers in attendance. Each carer's individual moving difficulties were acknowledged and then safe and appropriate moving techniques were demonstrated. Then all members of the training practiced the moving techniques. These carers learned, not only how to safely move and handle the person they cared for, but they also learned a plethora of other techniques that may come in handy in the future, thereby potentially saving future health problems for the carers. This approach was time consuming and added to the time translation required, hence the training had to be extended and completed on another day. This second day also allowed the trainers to bring in additional equipment to show the carers how aids and adaptations could further help their individual situations. Though this is an example of good training technique, it was particularly helpful to overcome language barriers.

Working with an interpreter is a skill, one which many health and social care professionals have not learned. The trainers did not have training in how to work with interpreters and according to this group of respondents was not ideal. Trainers in one course were “naturals” when working with the interpreter and used good body language, spoke in a way that allowed the translator to chunk the information to be translated, and interacted with the participants rather than the interpreter. Some of the other trainers were not as naturally skilled in this area. A second part of this project did do some training with professionals around working with interpreters.

### Lessons Learned

These respondents identified several key lessons that should be considered when taking forward similar work in the future. The first is the importance of partnership working. New links and partnerships have been established as a result of the project and this will prove useful in the future. Some organisations that are working or wish to work with BME carers may not be as well developed or strong as other agencies working with BME carers. These organisations and the lone cultural outreach workers need support. Partnership approaches may be a way to help build capacity across organisations and regions.

Doing this type of community development and capacity building work is resource intensive. MECOPP had time and money to do this work and be an enabling agency. Other agencies are at full capacity and had to really stretch to do this work. Without resources it may not be sustainable.

### **Discussion of the Black and Minority Ethnic Carers Training Project**

Two of the objectives of this project were to support and improve carers' emotional, physical health and wellbeing and to support and develop carers' skills and knowledge. Based on the evidence described above it appears that these objectives have been met. For example, every question on the evaluation questionnaire relating to carer outcomes indicated a positive change. However, these overwhelming positive changes indicated in the data bear closer scrutiny as it seems unlikely that attendance at a training course, no matter how excellent, would have such far reaching impact. At the same time, it is not necessary to discount the results because of the unlikelihood of such a finding.

These positive findings may have occurred due to how the questionnaire and training evaluations were administered. Though the questionnaires had been translated into Chinese and Urdu, the participants still required help to fill out the questionnaires due to illiteracy in the native language. There may have been social desirability at work in the higher responses at post test. Participants in the focus groups were extremely grateful for the courses and any attention and support was seen as a good thing. The trainers, interpreter, cultural outreach workers and course organisers echoed this sentiment. As such, the carers may have wanted to please the project workers by indicating positive responses at post test. In addition, there were relatively small numbers completing the questionnaire at both pre and post test. Due to an oversight most of the Asian carers only received the pre test.

Another explanation may be that the carers scored particularly low at pre-test. Most mean responses were on the negative end of the scale, and with such low scores to begin with, simply the passage of time may lead to an improvement of scores. This is known as statistical regression. On the other hand any additional support may have led to more positive responses when one starts out so low.

In reality, there probably is some social desirability and statistical regression occurring within these results. However, the qualitative data also suggest that the training courses helped improve carers' knowledge and skills as well as health and well being. The focus groups with the carers and the interviews with trainers, outreach workers and course organisers all indicated that these carers had a dearth of support, information and training prior to this project. Many of them also had bleak and isolating caring situations. So when starting from such a deficit, being offered support for the first time is bound to improve some areas. Certainly there were numerous examples of increased knowledge and skills as well as taking better care of oneself within all the qualitative data. These qualitative data would support what was found in the questionnaire and the training evaluations. The Chinese Moving and Handling course is a good example of this. It is probably safe to say that the first two objectives were met, but probably not as strongly as the quantitative data suggest.

Some other findings are worth noting at this point as they were consistent across several sources of data. First, it appears that the importance of outreach and community development approaches cannot be overstated. Carers, trainers and course organisers all discussed how vital it was to have a bi-cultural worker who could reach out and help the carers enter into and navigate this new world of carer training. This is a slow and laborious process, but important to the success of engaging marginalised groups of people and building community capacity.

The focus groups and information from the trainers and outreach workers also support several benefits of the training beyond increased knowledge and skills. For example, carers received many referrals and access to needed resources and adaptations as a result of the training. Carers also described increased confidence in their caring roles and feeling less stress. The new knowledge and skills also were cascaded beyond the individuals who took the courses as they shared the information with family and friends.

The power of mutual aid and social support was also an important finding that was echoed across the various sources of data. Bringing these carers together helped to combat some of the isolation they experienced. They also were able to support and learn from one another. These benefits go beyond the content, knowledge and skills.

The Black and Minority Ethnic Carers Project had additional outcomes beyond the provision of training. These included objectives concerning the development of partnership with mainstream carers organisations. The partnerships were envisioned to build capacity in and support partner organisations in their efforts to support carers from BME communities.

By and large, establishing these partnerships was successful. For example, training local authority staff on how to work with an interpreter was well received. However,

barriers to successful partnership working were encountered in all the projects. These included resource issues (e.g., the considerable time required for staff from the project and the partner agencies to establish the partnership working arrangements as well as carry out the partnership work), political issues (e.g., working across boundaries and being sensitive to the work of other existing organisations, working through differences of opinion, and confronting different priority levels for BME carers), and other organisational and environmental challenges (e.g., changing staff, differing relationships across partners, under resourced partners).

Given the short timeframe of this project, it is highly commendable that such complex issues were sufficiently dealt with to deliver outcomes in most partnerships. Except when partner organisations ceased to exist, sufficient progress was made in partnership development to warrant further development of the partnerships. Time and continued sensitivity are required.

## Results for the Highland Carers Training Project

As indicated elsewhere in the report, the pilot project targeting carers from rural communities was run under the auspices of Highland Community Care Forum. This project developed a programme entitled Carers Can. The initial work of the project included extensive scoping of carers' needs as well as training capacity with the Highlands. A programme of training courses was then developed to meet the identified needs. The courses developed were conceptualised at two different levels or tiers. Tier 1 was a basic skills course called, Caring with Confidence, that was meant to be a "taster" training course. It covered things such as stress management, communication skills, dealing with guilt and changing relationships and relaxation. It was hoped that this course would introduce carers to the concept of training and get them ready for more training. Tier 2 courses were condition specific or topic specific courses created. These were:

- Navigating the system – what do social work and health provide, what is available from the voluntary sector. How to access support.
- Planning for the future – what carers of all ages need to know to ensure that they are able to plan effectively and timeously.
- Moving and assisting – how to support the cared for person to move without injuring either party

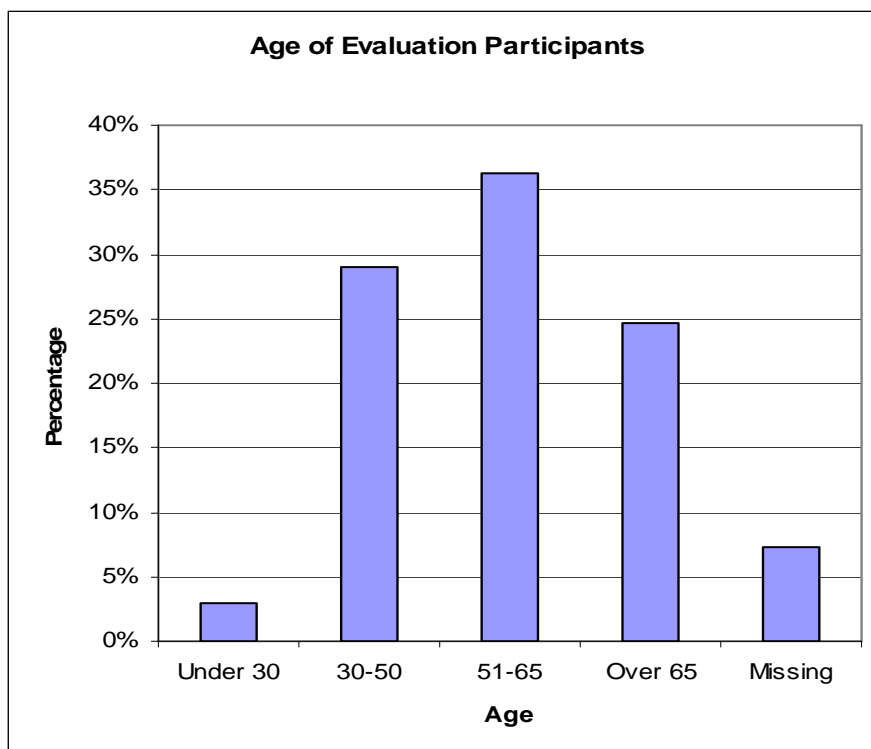
### Participants in the Evaluation

A total of 69 carers participated in the questionnaire portion of the evaluation. The participating carers came from across the Highlands though as can be seen in Table 4 over a quarter of carers came from the Inverness area. Table 5 indicates which courses the carers took. It should be noted that Planning for the Future had two different versions. One was for people taking care of younger people and one was for older people. The figures in Table 5 did not differentiate between the two versions.

<b>Area</b>	<b>Frequency</b>	<b>Percent</b>
Inverness	18	26%
Unknown	13	19%
Dingwall	12	17%
Tain	5	7%
Wick	5	7%
Aviemore	4	6%
Invergordon	3	4%
Thurso	3	4%
Boat of Garten	3	4%
Nairn	2	3%
Brora	1	1%
	69	100%

As can be seen in Figure 4, most of the carers were over 50 years of age. As would be expected the overwhelming majority (77%) of the carers were women. Only one carer identified herself as something other than White Scottish or British. Nearly 50% of the respondents were caring for a child or children, though 20% of the respondents were caring for an adult son or daughter (see figure 5). The average length of time the carers had been in the caring role was 12.2 years, though the range was 4 months to 40 years. They were providing care an average of 18.1 hours a day with a range from 1 hour to 24 hours a day. The respondents were by and large substantial heavy duty and long term carers. Approximately 40% of the carers were caring for someone with a learning disability and/or autism (see Table 6) and surprisingly only 33% of the carers reported caring for someone with a condition typically associated with ageing (e.g. Neurological Conditions and Arthritis).

	Frequency	Percent
Planning for the Future	19	28%
Moving and Handling	9	13%
Navigating the System	9	13%
Caring with Confidence	23	33%
Unknown	7	10%
Stress Management	1	1%
Navigating the System & Planning for the Future	1	1%
Total	69	100%



**Figure 4**

As the carers had been caring for so long, it is surprising to see that so few reported ever receiving any training in the past. In fact, 61% reported never receiving any training at all (Table 7). Another 7% received some training, but not as a carer as the

training occurred in a previous career. For example several of the carers had been nurses but had to give that up to become carers. Another 9% had only recently received any training as a result of this pilot project. Without this project or previous work experience, only 9% (n=6) of the carers in this sample had received any carers training and two of these respondents indicated that the training occurred in a support group, so may not have been formal carers' training.

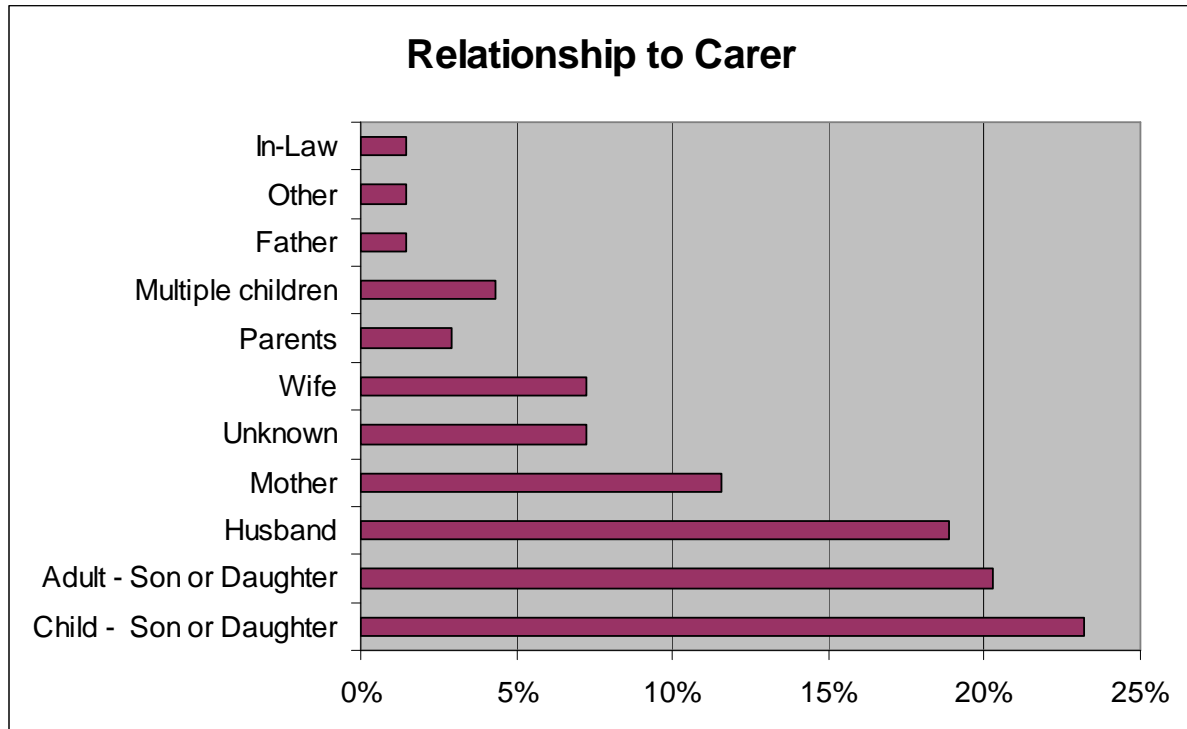


Figure 5

Condition	N	%
Profound and Multiple Learning Difficulty	12	17%
Neurological Condition (stroke, dementia, Parkinson's disease, MS)	11	16%
Other Medical Condition	10	14%
Autism	7	10%
Mobility/infirmity	7	10%
Arthritis	5	7%
Autism and Learning Disability	4	6%
Brain Damage	3	4%
Learning Disability	4	6%
Not reported	6	9%

69 100%

Training	N	%
None	42	61%
Not reported	10	14%
Prior Course in the Project	6	9%
Some previous training	6	9%
Previous career	5	7%
Totals	69	100%

The majority of participants found out about the Carers Can project through direct outreach efforts of the Highland Carers Project (See Table 8). Other voluntary organisations such as Crossroads and the Princess Royal Trust for Carers also referred some people to the project. Professionals referred 6 people to the project.

Source of Information	N	%
Highland Carers Project	38	55%
Informal Networks (friends/family/carers meetings)	6	9%
Voluntary Organisation	5	7%
Advertisement	4	6%
Social Work	3	4%
Highland Carers Project and Community Nurse	2	3%
GP	1	1%
Not reported	10	14%
Totals	69	100%

### Pre-test Post-test Carers Questionnaires

Out of the 69 carers who participated in the questionnaire, only 21 participants answered both the pre and post carers questionnaire. However, not all questions were answered at both points in time. As such, some of the questions had only 19 pairs for comparisons. The scores before and after the training courses were compared using a paired *t*-test. The results of the analysis are summarised in table 9.

Questionnaire Item	Mean Change	Std. Dev.	<i>t</i> -value	df	<i>p</i> -value
I am often very negative/positive about my caring situation	-0.57	2.04	-1.28	20	0.11
I do not/do feel very confident in my role as a carer	-0.43	1.63	-1.21	20	0.12
I do not/do manage my caring responsibilities well	-0.38	1.77	-0.98	20	0.17
My health is seriously affected by my caring situation/My caring situation has no affect on my health	-0.33	1.39	-1.10	20	0.14
My emotional health is seriously affected by my caring situation/My caring situation has had no affect on my emotional health	0.19	2.48	0.35	20	0.36
I frequently feel/rarely get stressed by my caring	-0.43	1.81	-1.09	20	0.14
There is nothing in my life except caring/I have plenty of other interests beyond caring	-0.55	1.70	-1.45	19	0.08*
I feel/rarely feel isolated as a carer	-0.65	1.63	-1.78	19	0.05*

I do not feel/usually feel supported in my caring role	-1.00	1.81	-2.48	19	0.01*
I am not/I am confident talking to care professionals about what I need	-0.25	1.65	-0.68	19	0.25
I feel I am unable/am able to work with care professionals as a key partner	0.05	2.06	0.11	19	0.46
My financial situation has been greatly affected/has been unaffected by my caring situation	-0.90	1.59	-2.54	19	0.01*
I know little about course topic/I feel knowledgeable about course topic	-0.95	2.09	-2.03	19	0.03*
I feel very unskilled/skilled in relation to the course I am undertaking	-0.95	1.99	-2.14	19	0.02*
I have a lot of concerns about the quality of care I provide/The quality of care I provide is to a high standard	-0.60	1.96	-1.37	19	0.09
This course made little difference for me as a carer/The course had a significant impact on my ability to care	-0.20	1.44	-0.62	19	0.27

\* indicates significance at  $p < .05$

These results suggest that carers had improving feelings of support, finances, knowledge and skills. In addition, carers felt less isolated.

As the number of paired responses was low, a second statistical test was run - an unpaired *t-test*. Here the pre-test and post-test were treated as different groups of people and their grouped responses for each question were compared across points in time. A total of 59 carers completed the pre-test and 31 completed the post-test. In the previous paired *t-test* each individual's own responses at pre-test were compared with their own responses at post test. This allows for a comparison of actual changes for each person which allows one to better control for confounding factors. Though the paired test is the more appropriate analysis for a repeated measures design, we wanted to see if the changes would still be present in the less sensitive unpaired *t-test*. In this analysis only the increase in feeling more knowledgeable ( $t=-1.93$ ,  $d.f.=87$ ,  $p=0.029$ ) remained.

### Focus groups with Carers

As indicated earlier, face to face and telephone focus groups were held with carers across the Highlands. A total of 20 carers participated in the five focus groups. The face to face groups were held in Dingwall and Thurso to ensure that the voices of rural carers were heard in the evaluation. In addition, telephone sessions were scheduled to facilitate participation from across the large geographic area. The focus groups were recorded and analysed using thematic content analysis. The questions on the interview schedule served as the initial thematic analytical framework. In addition, the analysis allowed for themes to emerge from the conversations participants engaged in with the focus group leaders as well as amongst themselves.

### Course Content

Though the carers could not necessarily remember the names of the courses they had attended, they quickly identified content from each of the courses. Most had gone to more than one course and saw them as a "suite" of training. They identified content such as learning to move a person without doing any damage to yourself, how to take care of yourself, knowing where to go to get the help you need, dealing with stress. In addition, all the carers in the focus groups indicated that it was not just

the content that was important, it was also the contact with other carers. Finding out that they were not alone was important.

When asked if the courses covered what they thought they should have, participants indicated that they did, for the most part. Participants in the focus groups were a mix of long term carers and newer carers, and for some of the long term carers some of the information was too general for them. Still, even these people were able to identify things they learned and found useful, despite some of the generalities. For example, several carers indicated how much they enjoyed the moving and handling training, but they found the general skills difficult to implement when back home. A follow up session that specifically addressed their needs was asked for. For several of the carers, this was the first carers training they attended so they did not know what to expect, and some of the information was surprising to them. For example, the Planning for the Future course was an eye opener for many of the participants. As one carer put it, "it was a kick up the backside. It made me think of things I didn't want to." Several of the carers were surprised that they would receive help from the other carers in attendance.

The carers felt the courses were very relevant to their caring situations. Though people cared for people with different conditions or ages, the carers felt that for the most part carers' issues are similar. They were able to benefit from the mix of experiences. At the same time carers indicated that not all the information was relevant to all the carers, but they stated that by necessity the trainers had to keep some things general.

#### How the courses were delivered

The carers reported that all the courses were excellent and indicated getting a lot out of them. They were able to offer some constructive criticism of the courses in the spirit of making the courses even better the next time they run. The first critique was that the courses felt very full or "cram packed." Carers discussed how they all could have been longer so that more material could be covered and there would be even more time to discuss with the trainers and other carers. This was especially true for the Caring with Confidence course. They felt that extra time would also allow for more advanced content to be delivered. At the same time, the carers understood the time constraints faced by the course planners and participants (e.g. distances travelled, difficulty getting replacement care), and the course was really valued as it was. The second critique dealt with a specific course. The Planning for the Future course was divided into a course for carers for older and younger people. Some carers were unclear what the difference was and felt that they may have gone to the wrong one.

The focus group participants felt that a general course like Caring with Confidence was very good and needed. Courses about specific topics are needed as a follow up or next step of training as well. The carers indicated the importance of having courses in different areas within the Highlands and not just in Inverness. The course around the Highlands were greatly appreciated and the participants indicated that travel expenses and help with replacement care was invaluable. This removed some difficult barriers for some of the carers.

## Cultural Issues

Initially there was some debate about whether or not there was such a thing as Highland culture within the focus groups. Some carers reported that the mentality of Highland culture is to be tough and take care of things yourself. You are not supposed to ask for help, nor are you supposed to make personal problems public. These people thought that this aspect of culture did make asking for help more difficult for Highland people. Other people felt that this was part of the caring experience no matter where you were from.

There was consensus across the focus groups that the rural nature of the Highlands, the sparse population dispersal and the distances between settlements and towns did make caring more difficult. Distance and lack of resources (e.g. care workers and respite) makes caring difficult and can make attending training difficult / impossible. The carers stated that isolation is an issue in caring generally, but they believed that rural carers have even more difficulties with isolation. These factors made it more difficult to agree to come on training, but the carers reported that the outreach work done by HCCF workers made the difference. The support, encouragement and assistance provided by the workers enabled those reluctant to attend to come.

The carers expressed regrets that more carers were not involved in the training courses, but at the same time thought that organisations and funders need to recognise the rural nature of the area and lower expectations of how many people it takes to make an event worthwhile. This would mean moving away from being too Inverness focused. They felt that one of the strengths of this project was its cognisance of the rural nature and how it took steps to try to address rural carers.

Though the carers discussed many difficulties with caring in remote and rural areas, they were also quick to point out that there are many positive aspects to rural caring as well. For example, some members described times when their child with a learning difficulty acted inappropriately or bizarrely in public, as everyone knew the child and the family they were accepting and supportive rather than scornful or vindictive. Some who had moved to the Highlands from the Central Belt or England described how the health service and some social services were actually better in the Highlands.

## Benefits derived from Attending the Courses

*Mutual aid* - The carers described many benefits they attributed to attending the courses. Though most of the benefits are directly related to the content covered in each of the courses, the carers in the focus groups unanimously agreed that mutual aid and support that occurred from meeting with other carers was especially important. For example, carers were reassured when they found out they were not alone in their thoughts, feelings and experiences. Other described how it was by talking to other carers they realised that they should and could start taking better care of themselves. Hearing how other carers dealt with similar problems gave them hope as well as practical tips. The carers felt that the courses were taught in such a way that it made this kind of sharing and mutual learning easy and natural.

*Accessing Resources and Financial and Legal Planning-* Another tangible benefit dealt with resources and finances. The courses provided a lot of information about benefits, entitlements, organisations, and other resources within various health and social care systems. Many of the participants immediately applied for these after the training (e.g. Council Tax reductions, carers allowance, aids and adaptations). Other carers learned all the different areas they needed to plan for and immediately began to put things like trusts, guardianship, power of attorney into place. Others began to talk with family members about such things for the very first time. Though for some people this planning was anxiety producing, most found it reassuring, and all felt it was very incredibly helpful.

*Receiving Information* - Related to both of the above areas, a major benefit that carers described is characterised by receiving needed information. Previous research has indicated that carers have a difficult time accessing the information they need (Kelly, 2006). The courses provided a great deal of information and several carers brought their information pack to the focus groups. The carers discussed the relief they felt in having so much information at the fingertips as typically they have to fight for any information. They discussed how they were sharing this information with family and friends.

*Taking Better Care of Self* – the carers also described how they were taking better care of themselves since attending the course...and doing so without feeling guilty. This included little things like taking 15 minutes away from the house to look at nature, finding time for a little bit of socialisation each month, and finding other ways for “me time.”

*Recognising stress and dealing with it* - The Caring with Confidence course included an exercise that brought home to carers just how stressed they could be and some of its negative effects on them and their families. This was an eye opener for many of the carers in the focus groups and they reported that they now recognise the signs of stress and learned tips on how to cope with the stress both from the course and also from other carers.

*Better Able to Deal with Professionals* – Focus group participants described the difficulties they experienced when dealing with health and social care professionals. They reported that many professionals do not listen to them, discount them, ignore them or worse. However, after the training several of the carers reported feeling better able to deal with professionals and had already put the lessons learned into practice with promising results.

*Reassurance and Confidence* – Focus group participants described how they felt reassured and more confident in their caring after the training. Even several of the long term carers (40+ years) indicated this. Knowing that they were doing the best for the person they cared for and had not overlooked anything major gave a peace of mind. Finding out that they were “not going crazy” or “really did know what I am talking about” increased their sense of confidence. Also, being armed with information gave carers a sense of confidence or feelings of empowerment.

### Next Steps Identified by Carers

The carers in the focus groups unanimously indicated that their next steps included more courses. They saw these courses as a suite of courses and they wanted to complete them all. For example, they thought the Caring with Confidence course was a good introduction and it whet their appetites for more training. The other courses seemed more advanced or more specific, and they would like even more specialised courses now to build on the foundation. Those focus group participants who did not attend all the courses indicated that they needed courses on those areas they missed (e.g. Legal guardianship, dealing with professionals, planning for the future, assertiveness training, aid and adaptations, moving and handling). They indicated that most of these areas were covered in the different courses offered, though more depth or time is required in some of the topics. For example, some assertiveness techniques were in Caring with Confidence, but it was a brief introduction. Other carers discussed the need for regular refresher courses or to further develop the suite of courses. Two participants indicated that they were now thinking about a career in caring and would be looking at vocational courses as well.

The carers indicated that some of the next steps for Highland Carers Project included developing these and other courses. They also felt that more carers needed to be recruited and that more efforts are required for reaching out to hidden carers. Several members also indicated that they thought more support for young carers is needed.

### Information for Policy Makers or Service Providers

Focus group participants were asked to indicate what they would like policy makers and service providers to know about what it is like to be a carer from the Highlands. There was a strong consensus that policy makers and service providers need to understand what it is like to be a carer and many were willing to have people “shadow” them for a day. They felt that then the policy makers and service providers would really understand that more courses/training/support for carers is needed. The participants also felt strongly that health, social care and education professionals need better training and education about carers’ issues. They also wished that policy makers and providers knew how difficult the benefits system and other bureaucracies make their lives. The financial impact of caring also needs to be better recognised by these officials. Finally, there were some strong opinions expressed about how services, supports and decision making power are too focused on Inverness. More projects should be like this project which really tried to provide services across the Highlands.

## Interviews with trainers and course organisers

Telephone interviews were held with the trainers and course organisers. These interviews focused on the same areas as the focus groups with carers but from the professionals' points of view. In addition this group of professional respondents were asked about barriers they faced in developing, designing or running the project. They were also asked specifically about any lessons they learned along the way. As the numbers of each group are small the results are described together to protect the confidentiality of the respondents.

### Barriers

The Project Lead reports taking a systematic approach to developing the pilot project. It began with a scoping exercise that helped to highlight some of the barriers the project was likely to encounter. Some of these things included transportation difficulties, need for providing care workers to look after the cared for people, difficulties with travelling long distances, diverse and widely spread out communities etc. In addition, the trainers and course organiser understood that being in small rural communities could make people less likely to be willing to share personal difficulties openly as well as the fiercely independent nature of some Highland people.

The courses were all designed with these potential barriers in mind. For example, the Caring with Confidence was purposefully designed to be relaxed, participatory, safe, using non-threatening activities and filled with positive group dynamics. It was a "taster" course to prepare people for further training. Courses were offered across the Highlands to help minimise distance barriers. Carers could claim for transportation costs and help was available for providing a care worker while the carer was at training.

In addition to individual course design and a programmatic approach, the Project Lead did a lot of outreach and "pre-training" work. Carers were reportedly reluctant to come and some did not recognise themselves as carers.

### Benefits to Carers

These respondents identified several benefits to carers that they were aware of either through seeing these on the day of training, at subsequent training sessions, or through follow up conversations with the carers. These benefits are summarised below:

*Mutual aid* - meeting with other carers and the support/mutual aid this facilitated was thought to be an important benefit to the carers.

*Information Provision* - Carers were given a great deal of information to overcome the known lack of information and difficulty receiving information. This information provision included course delivery and information packs given out on the day of training, but also follow up information was sent to carers where appropriate.

*Improved Finances* – Information about council tax and benefits was given and discussed with carers. Many carers did not know about these benefits and described “light bulb moments.” The carers reported that they went straight away to the council to apply for what they were entitled to.

*Information Cascade* – Information was passed on to carers who were reluctant or unable to come by those carers who did attend or through staff.

*Respite* – Coming to the training was a break for carers. The project purposefully chose nice venues and provided a nice lunch to facilitate a sense of respite.

*Carers felt listened to* – Carers reported to trainers after the courses that they actually felt listened to for the first time and were amazed that people were asking how they were.

*Reduced Stress* – Carers reported to the trainers that they did not realise how stressed they were, but they now recognise the stress and picked up tips with how to deal with it.

*Taking Better Care of Self* – Carers reported to the trainers that they were given permission to take care of themselves without feeling guilty.

### Cultural Issues

As indicated earlier, the trainer and Project Lead were aware that being in small rural communities could make people less likely to be willing to share personal difficulties openly and they were aware of the fiercely independent nature of some Highland people. The respondents indicated that many carers in the Highlands were not used to training or getting help. The Caring with Confidence course was designed to help overcome some of these cultural or regional factors. It was envisioned to be a “Strupag” meeting, which would be in keeping with Highland culture. (Strupag literally means a cup of tea in Gaelic, but in this context it connotes a sense of a social or informal gathering.) At the same time, they indicate that there is not uniformity within the Highlands. Communities and their needs can be very different. As such a community development approach is necessary in order to develop and/or deliver appropriate courses and services in the different areas.

### Lessons Learned

The trainers and Project Lead identified several lessons they learned through working on this project. For example, the importance of taking a community development approach was seen as crucial to the success of the project. According to the Project Lead, they started from a place where people did not have anything or there were huge gaps between training - even a little bit of training might make a big difference for people who have nothing. She reported that it was important to find the key people who could open the doors in the different communities (e.g., Chair of local Carers’ fora). As many carers were coming from a place of never having had training and/or being unsure or reluctant to try, a community development approach to building local capacity was important. As indicated earlier, the Caring with Confidence course was designed to build the capacity of carers to engage in further

training and support activities. However, this capacity building began prior to the first course. As part of the scoping exercise, focus groups were used to find out what carers needed and wanted, but they served another purpose as well - as a means of getting carers ready to engage with training and support. Outreach and pre-training engagement were central to this approach. However, it must be recognised that this is a long term and time consuming approach.

Some lessons were also learned about the delivery of the different courses. Some of the courses may have been too basic or too general. For example, Navigating the System may not have had as much benefit as it could have as it was generic. The systems that parents caring for a disabled child must navigate will have some very different components from the system a carer for an older person with dementia will have to navigate. Working with partners in the course delivery is important as well. For example working with the Citizens Advice Bureau and a solicitor to do the Planning for the Future Courses was very helpful. Professionals should be involved in the next round of course delivery; however due to the high level of negative feelings about professionals, choosing the right professional partners will be critical.

Lessons about location of courses were also learned. There is a tension between making things as local as possible with having training held in larger towns so that carers can take care of business before or after a training event. For example, the group in Brora would have preferred to go to a training course in Dingwall so that they could use the day out to also go to the 'big shops'. Other carers would not have been able to attend sessions if they were too far away. A mix of local and further afield training events would probably work best.

Recruitment lessons were also learned. As was described earlier, a great deal of outreach and pre-training work occurred and this was part of the recruitment process. Advertisements were placed in local newspapers and this worked in a few places but not others. Going through existing networks was the most fruitful way of recruiting, but other efforts must be tried in order to reach more hidden carers. Possibilities include asking carers to invite a friend to future caring courses and putting on training in non-traditional venues.

There were some areas where organising efforts were not successful. For example, efforts in Lochaber did not yield any results. Though the exact reasons are unclear, it may be efforts from Inverness raise certain barriers or that the HCCF does not share the same networks as carers in the area. More preparatory community development work may be required and that will take more time than was available in this pilot project. Skye was another area where efforts were not successful and planned events had to be cancelled due to lack of uptake. A similar community development approach was used in Skye, but unlike other areas, there were not already established community networks that the project could tap into. With the existing relationships in the other areas it was more straightforward and quicker to get into the communities and reach carers. Future efforts in Skye will focus on starting where the carers are and building on some newly developed relationships.

## Discussion of Highland Results

Two of the objectives of this project were to support and improve carers' emotional, physical health and wellbeing and to support and develop carers' skills and knowledge. Based on the evidence described above it appears that these objectives have been met, especially in relation to improved knowledge. The questionnaire results suggest that, at the very least, carers felt more knowledgeable in relation to their caring role, as there were statistically significant changes identified in both statistical analyses in this area. In addition, the analysis that took into account where each individual carer started from prior to training also found that carers felt more supported, more positive about their financial situation, more skilful in relation to their caring role and less isolated. Because the numbers of participants completing both the pre and post-test was low we do not have as much confidence in these results as we would like. However, when considered alongside the data from the focus groups with the carers and interviews with trainers/course organisers, one can have much more confidence in the results.

Take for instance the finding about improved finances. The statistical analysis suggested that carers felt less negative about the financial impact caring was having on their lives. In the focus groups with carers, most of them indicated finding out about benefits and supports that they were entitled to as part of the courses. They also indicated that they acted on the new information almost immediately after the course. The Project Lead and course trainers also reported witnessing "light bulb" moments when carers realised that they were entitled to receive assistance and were making plans to access such. Taken together, these data strongly suggest that the courses did have a beneficial financial impact on the lives of many of the carers in the training.

The statistical analysis also suggested that carers may feel more supported in their caring role and less isolated as a result of the courses. Again, the focus groups with carers support these findings. The focus group participants spoke at great length about the support and mutual aid they received from other carers. They also spoke about feeling that the Carers Can project was on their side. In addition, they described the referrals to other support services, the provision of information, and other instrumental supports provided through the course. These supportive activities were echoed by the interviews with the professional staff. Taken as a whole, these data do suggest that carers felt more supported as a result of these courses, and we are provided with some explanations as to why that is the case.

The increase in knowledge is most strongly supported by the quantitative data as it was consistently found across both statistical tests. These findings are also strongly supported in the qualitative data. The provision of information was a common theme across all the qualitative data and of vital importance to carers. We know that carers have a very difficult time accessing information they need, and as these courses were information rich, it is not surprising that this is such a consistent finding. Increased skills were also identified in the qualitative data. These skills included better moving and handling skills, but also an increase in communication skills for dealing with professionals, as well as self-care skills. Again, the triangulation of data strongly supports that the courses had a positive impact on carers' skills and knowledge.

A third objective was to provide opportunities to enable carers to have “an ordinary life” including the opportunity to take part in education and lifelong learning and learn skills to enter or return to employment. This project has given carers the opportunity to take part in education and lifelong learning. However, the objective for learning skills to enter or return to employment is probably an unrealistic objective for most carers within this short pilot project. For many carers this was the first training they had participated in. The Project Lead spoke about the incredible efforts she had to go to in order to encourage and support people to attend. This was an exercise in capacity building, and for many of the carers their caring roles have placed them at a great disadvantage for learning and personal development. A long term approach of capacity building and community development will be required to reach many of these carers. On the other hand, there will likely be a much smaller number of carers who are at a very different place. For example, two of the carers in the focus groups discussed all the skills they have acquired as a result of their caring roles and are thinking about pursuing a career in caring. They have started to look for vocational qualifications they can take while continuing their current caring role. They report that these courses have supported them in this process.

Some other important findings emerged from the qualitative data, rather than the statistical data. Focus group participants and course trainers identified benefits of the training that are related to but outwith the discussion above. For example, the carers in the focus groups described how they were taking better care of themselves as a result of the training. The trainers echoed this. Part of taking better care of oneself is recognising and dealing with stress and the carers in the focus group discussed this at length, and this was again echoed by the trainers. The carers also described feeling more confident and reassured in their caring, and trainers echoed this in their observations that carers felt listened to and understood for the first time in a long time.

Some process findings also emerged from the qualitative data. The first relates to the importance of outreach to carers. Many of the carers described how the Project Lead really worked to reassure and support them to try one of the courses. The Project Lead and trainers also described the importance of this. For example, the Project Lead described how important, yet time consuming, it was to contact, connect with, support, problem solve, and encourage the carers to try something new like the Caring with Confidence course. Simply turning up in a community to put on a course would not work in the Highlands. A lot of pre-training work is required.

The second important process finding is the importance of understanding and overcoming barriers faced by carers in the Highlands. The Project appears to have really understood the barriers and put in place many things to overcome them. These include trying to cut down on distance by moving the training around, assisting with travel expenses, being able to provide replacement care so carers could actually get away from their caring, designing the first course as a capacity building training experience, attempting to incorporate cultural aspects into the training, and doing an in-depth and participatory scoping exercise to ensure that they were delivering what carers wanted and needed.

## **A View across Both Projects**

Across both projects 103 carers participated in the questionnaire component of the evaluation and 75 were involved in focus groups. An additional 32 carers completed a training evaluation for some of the BME courses. When the data for both projects are pooled all 16 questions concerning carer outcomes indicate a significant positive change from pre-test to post-test. The strong changes in the BME carers' data exert influence over the pooled data. Though with increasing numbers statistics usually become more reliable or generalisable, in this situation it is probably safest to view the statistics separately due to reasons described earlier – namely uncertainty of the effects of social desirability and statistical regression in the BME data. It appears that changes did occur on key project outcomes in both projects, especially when viewed alongside the qualitative data, however we must be conservative with how much change we ascribe to the courses in the BME project.

When considering the qualitative data we can be more confident in the findings. Interestingly, despite very different cultural and geographical areas, there are some surprisingly similar findings across both projects. These will be described below.

### Isolated Carers Hungry for More Training and Support

First and foremost, the courses were overall well received by carers in the Highlands and from BME communities and the carers were hungry for more training and support. The reasons for this hunger are similar in both groups. Both groups are isolated and underserved. The reasons for this will be different as BME carers face language and cultural barriers and carers from the Highlands face distance and rural barriers. However, the end result for both groups has been the same – caring in isolation

### Importance of Outreach, Capacity Building and Community Development

Interestingly, many of the strategies for overcoming barriers appear to be the same. Both projects attempted to use community development and capacity building approaches. This included a great deal of time and effort spent on outreach to individual carers, but also to key people and organisations within communities. For example, in the Highlands the Project Lead had to telephone individual carers and encourage and support their efforts to attend training. Community outreach workers had to do the same in the BME communities. In the Highlands it was important to find key partners and try to reach out to carers through them. This was the same for the BME project. Carers in both groups were not used to training and had to be prepared to undertake what was being offered. These efforts cannot be overstated.

### Working with Established Network Relationships

Working with established relationships was very important and facilitated the development and implementation of courses. Where these existed it was possible to reach carers and deliver training. Difficulties occurred where relationships did not already exist as these relationships take time to nurture and develop. For example,

efforts in two areas in Highlands did not come to fruition. Yet in one of the areas a relationship with a network has now been formed and development work is possible in the future. In the BME project, relationship building with key partners in a semi-rural location was fraught with difficulties. However, work with several of the key partners has led to a newly formed productive relationship. Given the time constraints of the project, work was not able to proceed further at this time. However, there is hope for future developments if resources to support this work are available.

### Time Constraints

Time, on various levels, was an issue for both projects. Due to the need for a lot of preparatory work, developing and delivering training for Highland and BME carers is a time and labour intensive endeavour. This was an ambitious project for an 18 month time period, and given more time more of the development work could occur. MECOPP lost its Project Lead midway through and this added to the time pressures for them.

The outreach work was also labour and time intensive for both projects. Future developments will need to find ways to resource the time required for outreach if we are to reach these isolated carers. It appears that carers from BME communities are even more dependent on outreach workers to access training.

In addition, there are time constraints for individual courses as well. Due to the difficulties faced by carers in getting to training a tension exists between giving as much information and support as possible in limited time and giving things proper time and attention. Carers in both projects indicated that they wished the courses could be longer. At the same time they realised the difficulties this would cause – both for them as carers but also for organisations providing the training. Course planners did agonise over this dilemma, and without significant resources for travel, respite provision, translation, and trainers time, this will always be a difficult choice.

### Benefits

The benefits of carer training were similar across both groups. A key area seems to be an increase in information. In some ways this should not be surprising as lack of information is a universally difficult area for carers in general. Carers from rural areas and especially from BME communities appear to have an even greater dearth of access to information. Regardless of what course or courses were taken, carers received information on aids, adaptations, resources and supports that could be of benefit to them. Each course also provided some information that could be translated into skills. Carers valued this new information so much that they have begun to cascade that information to other family and friends.

Mutual aid was another benefit that cuts across both groups. Given that these were isolated carers it should not be a surprise that they all indicated the importance of social support, mutual aid and finding out that they were not alone.

Taking better care of oneself is another benefit that was described by carers from both projects. This could be anything from taking time out from caring, recognising

and dealing with stress, safer moving and handling techniques, better nutrition, gentle exercise to incontinence training exercises.

Though there are other examples of benefits to carers, they all relate to increased knowledge and skill in relation to the caring role as well as improved health and well being. It appears, then, that the projects did demonstrate the ability to impact on these key areas from the objectives of the overall project.

### Participation in Education and Lifelong Learning

Another goal of the project was to provide opportunities for carers to have “an ordinary life” including the opportunity to take part in education and lifelong learning and learn skills to enter or return to employment. Given their caring situations any programme would have difficulty in providing an ordinary life, whatever that may be. However, as will be apparent in the separate reports written by the individual projects, both projects delivered in the area of providing education. In addition, two carers from the focus groups in the Highlands indicated they were moving towards more training in caring for an eventual return to work in paid care work. In the Chinese group two participants may receive additional training to be volunteer outreach workers. Though anecdotal, these examples suggest that carers training can have implications for lifelong learning and potentially for return to paid employment.

In order to deliver on this goal of lifelong learning and potential return to paid employment, a strategic, systematic and long term plan must be developed. A blue print exists in one of the projects.

The BME project developed training to meet the immediate needs of carers based on some initial scoping. Discrete training courses were developed to meet the needs of discrete groups of carers from BME communities. For example, a group of SE Asian carers was suffering from arthritis and this was making their caring more difficult. Developing a course to teach them to take better care of their own condition as well as supporting them in their caring role was important. Such courses could be developed for other carers as well, so the pilot served a useful purpose in developing a new type of carer training. The Chinese carers in Dundee needed a moving and handling course to help them be better carers. Not only did this course provide great benefits to the participants, but in the process of developing and running this course a host of invaluable and transferable lessons were learned. However beneficial this approach was to the immediate needs of those carers, this approach is not as strategic as required to deliver on higher level objectives.

The Highland project, on the other hand, does supply a potential blueprint for delivering on this objective. Their initial scoping exercises started with a dual purpose. The first was to assess need and the second was to begin the capacity building process. Carers in the Highland were not used to training of any kind, let alone education for lifelong learning or return to work. As such, they had to get used to the idea of training and learning how to learn. The two-tiered approach they developed built on the initial capacity building in the scoping focus groups. The tier-1 level provided a lot of information and support for caring, but it was also designed to get carers used to learning and training in an organised setting. The tier-2 courses

then built on this and were developed as a suite of learning that people could dip in or out of based on their own needs. Rather than developing a series of one-off courses, the Highland project developed a learning pathway for carers that was responsive to local needs. Such an approach has the potential to improve the lives of carers by providing them with the knowledge and skills and supports they need in their caring role, but it also has the potential to provide the skills and some opportunities for lifelong learning.

#### Information to form a comprehensive strategy for carers' learning and development

The final objective in the grant was to provide a sound knowledge and information base to form a comprehensive strategy for carers' learning and development. Certainly both projects within National Carers Organisations Carer Training Initiative have identified important lessons that can inform future developments in carer training, especially for carers from rural and BME communities. In addition, the lessons can help to form a comprehensive strategy as well. Based on this project, key points for this strategy should include:

- Local scoping of carer needs for and barriers to training
- Dual emphasis on capacity building for lifelong learning and training to meet carers' needs in caring
- Development of a suite of courses or a learning pathway
- Appropriate investment in outreach workers and other required supports such as trainers and interpreters
- Developing strategies for overcoming barriers identified in scoping exercise
- Developing a long term view of the process
- Investing time and energy into building networks with carers and carers organisations as well as health and social care professionals

## Conclusions and Recommendations

This evaluation has demonstrated that carers from rural and BME communities are able to participate in and benefit from carers training programmes. However, in order to participate in such programmes a good deal of outreach work is required – both to individual carers but also to existing networks and organisations. These groups of carers also face significant barriers that must be overcome to allow their participation. The preparatory and supportive work takes resources and time. Both of the pilot projects within the NCO Carers Training Initiative have demonstrated ways that this preparatory and supportive work can occur. In addition, a model of good practice has been identified. Based on these findings we make the following recommendations:

1. Carers training programmes should be developed and delivered for BME and rural communities;
2. The training programmes should be part of a long-term and strategic plan to build learning and development pathways that support knowledge and skills for caring as well as for lifelong learning;
3. The training programmes should be adequately resourced so that appropriate levels of community development and outreach can occur. Because of the small percentage of people from BME communities in most areas across Scotland, local governments may have difficulty allocating sufficient funding for such work when balanced against larger areas of need they face. As such, creative ways for financing such work should be found. Examples include, cross council funding or joint funding with health, education and social work;
4. Budget levels should be set to ensure that appropriate supports are available to overcome barriers to participation. Depending on the population this would include funding for transportation, replacement care costs, translation, and experienced trainers.

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