



UNIVERSITY OF
LINCOLN

Evaluation of the Older Carers Project Delivered by Every-One (formally known as Lincolnshire Carers and Young Carers Partnership, LCYCP)

Dr Jane Deville, Helen Davies and Dr Ros Kane

School of Health and Social Care
College of Social Sciences
University of Lincoln

Contributors

The evaluation team consisted of:

Dr Jane Deville, Research Fellow, University of Lincoln
Helen Davies, Senior Lecturer, University of Lincoln
Dr Ros Kane, Reader in Healthcare, University of Lincoln

The Steering group consisted of:

Mick Skipworth, Senior Commissioning Officer (Adults) LCC
Vicky Thomson, Chief Executive Officer LCYCP
Philip Burgess, Older Carer Project Lead LCYCP
Marie Cottam, Older Carer Project Co-ordinator LCYCP
Rachel Kelly, Principal Practitioner LCC
Peta Hill, Vulnerable Adults Programme Officer, Public Health
John Gurney, County Carers Group
Wendy Adams, County Carers Group

Ros Kane, Helen Davies, Jane Deville, David Nelson (Macmillan Research Fellow), Paul Mansfield (Senior Lecturer) and Nigel Horner (Head of School of Health and Social Care) from the University of Lincoln were also in attendance at planning meetings and Steering Group meetings.

Contact:

Dr Ros Kane
School of Social Sciences
University of Lincoln
Brayford Pool
Lincoln
LN6 7TS

rkane@lincoln.ac.uk

01522 837326

Acknowledgements

The researchers would like to acknowledge the help and support from the following organisations and individuals:

All members of the Older Carers Project Steering Group. In particular Mick Skipworth from Lincolnshire County Council and all staff from Lincolnshire Carers and Young Carers Partnership (LCYCP) who provided support and feedback throughout the project.

Nigel Horner who helped during the initial stages of planning the project and Alison Wilson who tirelessly helped organise the contract and finance.

All carers who freely gave their time to talk to the researchers about their experiences of the Older Carers Project.

Executive Summary

During early 2015 Lincolnshire County Council commissioned Lincolnshire Carers and Young Carers Partnership (LCYCP) to undertake the Older Carers Project. The project provided support for carers over the age of 55 who had grown up children with learning disabilities to produce contingency and future care plans. The aim of this was to ensure that when the carers could no longer continue in their caring role, sufficient plans were in place to avoid a crisis where their son or daughter may be forced into residential care causing unnecessary stress and expense. This evaluation talked to carers who had received support about their experience of the project.

A total of 12 semi structured interviews were conducted with service users about the support they had received from the Older Carers Project, the future planning they had undertaken and any benefits of the intervention. This enabled any strengths and weaknesses occurring across the initiative to be identified and recommendations for future interventions to be provided.

The evaluation found that the Older Carers Project had been a very successful project in helping carers set up emergency and future plans. The participants all held the support they had received from project support workers in high regard and valued having a service aimed at themselves rather than their sons or daughters. They talked positively about the flexibility of the support, the role and knowledge of the project support workers and the delivery of the project by a third sector organisation. In some cases the project had highlighted benefits and support that the carers did not know they were entitled to. Further work was required to ensure that project plans were shared and that the cared for person was included in any discussions where appropriate.

Overall the preparation of plans for the future had enabled carers to feel more settled and positive about the future for themselves and the future care their son or daughter may receive.

Contents	Page No.
1.0 Introduction	7
2.0 Methodology	10
2.1 Ethical approval and data sharing agreements	10
2.2 In depth interviews	10
2.2.1 Designing the topic guide	11
2.2.2 Collecting the qualitative data	11
3.0 Results	13
3.1 Initial contact with the Older Carers Project	15
3.2 Overview of the support received	16
3.2.1 Flexibility of support	16
3.2.2 Focus on the carer	17
3.3 Accessing services and resources	18
3.3.1 Emergency planning	19
3.3.2 Future Care Plans	19
3.3.3 Additional funding – respite and benefits	21
3.3.4 Signposting to other services and support	22
3.4 Benefits to carers of the support received	22
3.4.1 Isolation	23
3.4.2 Future support	23
3.4.3 Benefits of having a plan	24
3.5 Links to Adult Care Services	24
4.0 Discussion	26
4.1 Limitations of the evaluation	26
4.2 Discussion and recommendations	26
4.2.1 Recruiting carers to the project	27
4.2.2 Caring for the carer	28
4.2.3 Age of the carer and cared for	28

4.2.4	Flexibility of support	29
4.2.5	Role and knowledge of the project support worker	29
4.2.6	Continuous care and support	30
4.2.7	Sharing plans	31
4.2.8	Delivery by a third sector organisation	32
4.2.9	Meeting the person cared for	32
4.3	Conclusions	33
	Appendix 1: Ethics application and approval letter	34
	Appendix 2: Interview topic guide	40
	Appendix 3: Participant information sheet and consent form	42
	Appendix 4: Letter and Frequently Asked Questions Sheet used by LCYCP to introduce the project to carers	45

1.0 Introduction

The 2011 Census reported that there are 79,000 carers across Lincolnshire who provide unpaid support to help families and friends to live at home. Of these 10.5% (8,300 carers) are providing over 50 hours care a week and aged 65 and over. Many of these are likely to be caring for their elderly partner, but for some their caring role will be for an adult son or daughter with a learning disability and, as the population ages and those that have a learning disability live longer, the number of carers falling into this category is likely to increase.

A high proportion of these older carers may themselves have a chronic illness, disability or health problems which can be exacerbated by a lack of appropriate respite care or support. They are often socially isolated because of the constraints imposed by the caring role and, over time, both the needs of the cared for and the carer will increase. Without additional support it may become increasingly difficult for individuals to cope with the demands of looking after an adult with learning disabilities within the home and additional pressures may lead to increases in maintenance costs as well as unplanned and unwanted residential care and hospital admissions.

In acknowledgement of the particular difficulties facing older carers, Lincolnshire County Council (LCC) secured funding from the Better Care Fund to look at how it supports older carers who are looking after someone with a learning disability in their home. The objective of the project was to alleviate, or delay, a break down in informal caring relationships by targeting proactive, preventative support at carers who are particularly at risk of breakdown and ensure peace of mind for families by putting contingency plans in place. In order to achieve this the project took a holistic approach examining the whole family and wider support network. It looked at putting carers assessments and emergency plans into place and talked about planning for the future.

During early 2015 Lincolnshire County Council commissioned Lincolnshire Carers and Young Carers Partnership (LCYCP) to undertake the Older Carers Project. The project initially aimed to provide support for older carers over the

age of 75, although this was subsequently widened to include all carers over the age of 55 who had grown up children with learning disabilities. The project aimed to:-

- Ensure older carers are known to LCC to maintain their mental and physical health and wellbeing and thereby continue in their caring role.
- Alleviate or delay a breakdown in caring relationships and lessen the need for or risk of increased social care maintenance services or health services.

Phase 1 of the programme aimed to understand the needs of older carers and identify the resources and support available for them. As a result of this work LCYCP developed a Carers Community Support Directory along with a Planning for the Future Toolkit. Both of these were used by project support workers during Phase 2 to enable them to help carers develop a contingency plan for short term care and a future care plan for when the carer decides they can no longer care. As part of the support provided, Carers were referred for Carers Assessments, to the Carers Emergency Response Scheme (CERS), signposting local support available, discussing in detail housing and support options as well as signposting for wills, trusts and powers of attorney.

During 2015 the Older Carers Project steering group approached the University of Lincoln to undertake an evaluation of Phase 2 of the programme to independently assess whether carers felt there had been an improvement in their circumstances due to being involved in the project. The evaluation commenced during June 2016 with this final report complete by September 2016.

Following the completion of this evaluation Lincolnshire Carers and Young Carers Partnership (LCYCP) re-branded and changed their name to Every-One. However, throughout this report they are referred to by their original name of Lincolnshire Carers and Young Carers Partnership which was used at the time of the project.

Lincolnshire Carers & Young Carers Partnership (LCYCP) had a strong background in supporting unpaid family carers at strategic and operational levels

through being the trusted advisor to Lincolnshire County Council on carers services, delivery of carers information services and a wide range of projects. On that basis LCYCP were commissioned to deliver the Older Carers Project.

Every-One is a Lincolnshire based social enterprise and registered charity, that aims to work inclusively with everyone, to ensure that every one carer and people that are cared for, are at the centre of their own wellbeing. Every-One does that by developing and delivering a range of person-centred services and projects that work towards 'making wellbeing personal'.

2.0 Methodology

2.1 Ethical approval and data sharing agreements

An ethics application was made on to the School of Health and Social Care Ethics Committee on the 28th May 2015. This was approved on the 18th June 2015. Copies of the application and approval letter are included in Appendix 1. This application included copies of the Participant Information Sheet and consent form.

Following approval by the School of Health and Social Care Ethics Committee an application to carry out the evaluation was also made by Lincolnshire Adult Care to their Research Governance Panel. This explained why the evaluation was required, how it was being undertaken and any issues that needed to be considered such as data protection. The application was made on the 24th July 2015 and agreed by the Research Governance Panel.

In addition to the ethical approval a data sharing agreement was also set up between Lincolnshire County Council (LCC), Lincolnshire Carers and Young Carers Partnership (LCYCP), County Carers and the University of Lincoln. This outlined a framework for partners to share personal data and regulate working practices. The agreement was initially set up on 26th July 2015 and subsequently updated as required.

Due to their length copies of the application to the County Council's Research Governance Panel and the data sharing agreement are available on request.

2.2 In-depth interviews

In order to accommodate older carers and obtain as much information about the participants' experiences as possible it was decided to use semi structured in-depth interviews. The aim of these interviews was to explore the views of those carers receiving support from the Older Carers Project covering a range of topics.

2.2.1 Designing the topic guide

An in-depth topic guide was developed specifically for the interviews in this study in conjunction with comments from the Steering Group. The topic guide aimed to examine:

- How and why the carer had become involved in the project
- What the carer's experience of the project had been
- What services and resources had been discussed including the creation of emergency and future plans
- What changes had occurred due to the project intervention
- Any benefits to the carer of the support received.

A full copy of the topic guide is shown in Appendix 2.

2.2.2 Collecting the qualitative data

A total of 92 carers received support and all of these were invited to take part in the evaluation research by an LCYCP project support worker on behalf of the evaluation team. Only carers who had received support from a project support worker and completed their future plans were interviewed during the evaluation. All carers were aged over 55 and were currently caring for a son or daughter with learning disabilities. Only one of these sons did not still live at home. At the time of the invitation carers who agreed to take part were provided with a letter from LCYCP introducing the evaluation and providing further information. The carer's details were then passed to the evaluation team who contacted them by telephone to agree a suitable time and date for an interview. A total of 24 carer's contact details were passed to the evaluation team. Those contacted were randomly selected from the list and a total of 15 were spoken to, of which 12 agreed to an interview. Interviews took place between the 21st June and 13th July 2016.

Prior to the interview participants were reassured that their participation was voluntary, results would be anonymous and that they were able to withdraw at any stage if they wished to do so. They were then asked to read and sign a

consent form (Appendix 3). Interviews all took place in the carer's home and lasted up to 1 hour 20 minutes of which between 20 and 50 minutes was digitally recorded.

The digital recordings were transcribed, assigned unique ID codes and any personal information removed.

Interviews were independently read by two members of the research team, analysed using the established framework method (Ritchie and Spencer 1994) and processed using the software package NVivo 11.

3.0 Results

A total of 12 carers who had received support from the Older Carers Project were interviewed during this evaluation. Participants were recruited from across Lincolnshire, however the names provided, and therefore the sample taken, were biased towards residents in the south and west of the county as shown in Figure 1. This was primarily due to the number of referrals received from practitioners in different areas of the county.

Figure 1. Locations of participants and sample

District	Number of carers	
	Details provided	Random sample
Boston	0	0
East Lindsey	1	0
Lincoln	4	2
North Kesteven	0	0
South Holland	4	2
South Kesteven	9	5
West Lindsey	6	3

11 out of the 12 respondents were the mother of the disabled son or daughter who was interviewed, with the remaining respondent being the father. In two cases another close family member was also present during the interview (one husband and one daughter). Carers ranged in age from 57 to 78 (mean 66) with sons or daughters between 22 and 52 (mean 36.5). In some cases the disabled person was not the parents only caring responsibility. Two respondents had an additional disabled son or daughter living away from home, one cared for an elderly parent within their home and others also provided care and support for a disabled spouse or additional young child. This is summarised in Figure 2.

Figure 2. Details of carers interviewed and age of son or daughter

Carer	Age of main carers	Age of son or daughter	Caring responsibilities
01	66	39	2 disabled sons - one with foster family
02	72	51	Son
03	62	25	Son
04	58/70*	23	Son
05	67	38	Son
06	78	52	Son - living independently
07	69	38	2 disabled sons - one living independently - and elderly mother
08	61	42	Son and disabled husband
09	57	23	Son and disabled husband
10	66	22	Daughter
11	69	40	Son
12	65	45	Daughter and young son age 6
Average ages	66	36.5	

*Mother 58 and father 70 – both involved in care and present for interview

Carers were also asked about their own health. The majority reported some degree of ill health ranging from having survived heart attacks or cancer to ongoing conditions such as arthritis which may have a long term impact on their caring ability.

3.1 Initial contact with the Older Carers Project

The majority of carers had got involved with the Older Carers Project following a telephone call or letter directly from the LCYCP. In two cases the carer had been referred to the project by the wellbeing service or their Adult Social Care Practitioner and in just one case the carer had been proactive in contacting the project following the involvement of one of her friends.

For most carers this was the first time they had been offered any support aimed at themselves rather than their son or daughter. A number of carers stated that following the initial contact with the LCYCP they didn't really know what the project was about and certainly had little understanding that it would focus on helping them develop care plans in case of an emergency or for the future.

I didn't know what to expect. You only get a brief description of what it was. (Carer 9)

No, didn't really know what was involved. Just thought she was coming to talk to me about what it was like caring. (Carer 11)

We weren't really sure actually. We thought it was probably like a survey, asking similar questions to Social Services. But we weren't really sure at all. (Carer 3)

Most carers had therefore agreed to take part simply to find out what additional support may be available to them and highlighted that it was difficult to find information, or that they simply didn't have time to look for it as they were busy caring.

I thought it might help me. Anything going, you know. (Carer 2)

Just to see if there was anything that we could benefit from..... Because nobody tells you what's out there. And when you don't have a lot of time

to sit and play with computers and read endless pieces of paper you don't know what is out there. (Carer 7)

3.2 Overview of the support received

Respondents were very positive about the support they had received during the Older Carers Project both with respect to the project support workers and the information provided. All those interviewed highlighted the personal approach that the project support workers had taken and talked very positively about their skills and personal attributes. These are discussed in more detail below.

3.2.1 Flexibility of support

The aim of the project was to offer support to carers to produce contingency and future plans and the number, and length, of visits were not fixed. It therefore varied depending on a number of factors including the emotional needs of the carer, their ability to absorb information and their current situation with regards to future planning. The majority of carers received 3 or 4 visits, however one reported that she had received 2 visits and another that she had received 8 or 9. On average carers reported that the visits lasted approximately an hour, although again this varied and often depended on the type of support required and the needs of the carer. In one case the carer reported her second visit had been just half an hour to finish forms off, but in other cases carers reported that the project support worker had stayed “*quite a long time*” or “*as long as you wanted*”, but were unable to quantify the length of time.

Carers welcomed the flexibility to choose when visits took place as well as their duration. Some carers needed time between visits to carry out any actions required or simply to think about the decisions they were making and discuss them with relatives. When they had requested more time between visits this had been accommodated by the project support worker.

It was difficult to make that decision. And [project support worker] did help me with it because she said think about it and next time I come...it wasn't

just an instant decision. She gave me time to think about it and talk to [husband] about it. (Carer 8)

For other carers it was difficult to plan in advance due to their caring roles and they had found it easy to cancel or change appointments if required.

And I had to cancel but because we had each others mobile it was easy to cancel anyway. It was very flexible. (Carer 9)

3.2.2 Focus on the carer

It was evident from carers that they valued the service being focused on their needs rather than the needs of the cared for person and in the majority of cases they had not received a service like this before.

It's nice to see because usually carers get forgotten don't they? (Carer 11)

We'd never done anything like this before. It was always [son's name]'s needs but this time it was our needs. (Carer 4)

I'm used to paddling on my own. I've very rarely been offered any help at all. (Carer 6)

Carers also valued the opportunity to build a relationship with the individual project support worker and all were very complimentary about the worker who had visited them. The suggestions and recommendations made by the project support worker had not always led to an increase in resources for the carer, but in all cases there appeared to be a developing relationship where the carer felt supported and listened to. In some cases project support workers had also discussed their roles as carers which was mentioned as a positive by a number of the carers interviewed.

It just meant so much to me and my family. There is something out there. You're not left with nothing or nowhere to go. I know now if I get desperate I can pick the phone up. (Carer 8)

It was all done very professionally. [project support worker] was very good at her job. She didn't make you feel like she was intruding. The way she asked questions, she gave you the option if you didn't want. Very friendly and caring. The fact that she has a daughter with epilepsy. She knows what it's like. (Carer 11)

Despite the focus on the carer the project support worker also met the cared for person in the majority of cases, however none were involved in any of the discussions that took place regarding their future. In some cases it had not been possible for the project support worker to meet the cared for person as they were at a day centre or other respite care during visits.

3.3 Accessing services and resources

Respondents talked about a wide range of services and resources which they had discussed with the project support worker. Some of these were concerned with long term future planning whilst others provided a contingency for emergency care if required or were simply support services the carer was unaware of.

A number of carers talked about the lack of support they had received in the past and their difficulties in accessing services. In some cases this was due to the fact that carers received very little information and were therefore unaware of what services and support were available to them rather than the services just not being there.

It's alright making sure the services are there. But if people don't know about the services how can they access them? It is getting knowledge to people who are carers. (Carer 10)

3.3.1 Emergency planning

A number of respondents had been able to develop a Carers Emergency Response Plan which they did not have in place before. This service, run by Carers Connect through Lincolnshire County Council, helps carers organise what would happen to the cared for person in case of an emergency. These details are registered and the carer receives a Carers Identification and Emergency key fob which they can carry at all times. On this fob are a unique identification number and a 24 hour emergency phone number so that the plan can be activated if necessary. A number of carers highlighted their concerns about what would happen to their son or daughter should they be involved in an accident or unable to look after them due to an emergency. Five of the carers interviewed mentioned that they had been unaware of this scheme, but had been able to register since talking with the project support worker and one other carer had been prompted to update their emergency care plan with current information.

The main thing for me was the emergency response thing. Which I think was brilliant. I've always said when we've been out what would we do if we had an accident. What do we do with him. (Carer 4)

3.3.2 Future care plan

All carers had talked about future care plans with the project support worker. A number of carers implied that they had given some previous thought to planning for the future, however in most cases they hadn't made any specific plans and the visits from the project support worker were the motivation they needed to start the process.

We had thought about it because we are early sixties now. You have to start thinking about things like that don't you? (Carer 3)

It was a nice gentle push because it was like 'next week I expect you to have started it!'. I don't think we would have got round to it otherwise. Not that quickly. (Carer 4)

Pleased because it's forced me to update the care plan. It's one of those things you say you're going to get round to doing and never do so really helpful in that way. (Carer 9)

Only one carer stated that she “*didn't really want to think about*”, but even she had benefited from organising an emergency card and was aware that the project support worker had filled in a future plan although she wasn't sure who had copies of it.

One of the hardest decisions for carers to make is who will look after their son or daughter when they are no longer able to. Some carers had other sons or daughters who were willing to take on this role and be named in the long term plan, but in other cases the project support worker had been able to help carers identify appropriate future care. Some carers reported that the project support worker had provided them with details about suitable care homes which they had not had before and one stated they had been able to visit these homes and give two suggestions on their future plan. Another carer had made the decision that they would prefer their son to live with a foster family which was an option they had not been aware of prior to this project.

In addition to considering where their son or daughter would live, discussions about the future had also considered setting up wills and obtaining power of attorney. Where required the project support worker had been able to provide details of solicitors who were experts in this area.

I told her that we had been talking about it at Christmas that we must make wills because we kept putting it off. And she gave me a name. I got in touch with [solicitor's name] and I've now done that. (Carer 11)

In one case discussions around these topics had led to the conclusion that the carer and their long term partner needed to get married to secure the future of their disabled daughter.

Despite meeting the project support worker, and often being happy with the service they had received, a small number of carers implied that they still did not have a formalised plan that they felt totally comfortable with. In one case the carer was concerned about her daughter offering to take on future care and worried about whether this would work due to sibling relationships and poor health. Another carer stated that the health of her son was changing and in the future he may need additional care. She had made a plan, but was frustrated that she was unable to take any future additional needs into account within it.

We did agree that if anything happened to me and [son's] dad, my daughter would look after [son] but in retrospect it may not be a good idea because she has mental health problems. I do worry about that because I don't know how she'd cope sometimes. They are just like brother and sister; they rub each other up the wrong way. (Carer 1)

He isn't as bright as he was and my concern was what was going to happen to him as he needs more care. And the young lady and I investigated all avenues and there is absolutely nothing you can do. You can't make any provisions. It depends how [son] progresses. It's a case of 'Well if he needs extra care, we'll put extra care in'. (Carer 6)

Although the majority of carers had made detailed future care plans with the project support worker some were unsure who now had access to these plans and what had happened to them. In other cases the plans had been stored away and carers had not shared them with anyone, even those named within it.

I don't know where the information that she's got goes to. But hopefully it is in the system somewhere. (Carer 11)

3.3.3 Additional funding – respite and benefits

In a number of cases the project support worker had talked through whether the carer was entitled to additional benefits or funding for respite care. In some cases such appeals for more support had been unsuccessful, but in some cases

additional support had been obtained. For example one carer, who currently had no formal respite, talked about receiving some funding from Carers Connect which would enable her to either take her son away for a weekend or give her and her husband the opportunity to spend some quality time together. Another had been put in touch with Age Concern who had been able to help her claim some additional benefits as she recently been forced to retire on the grounds of ill health.

3.3.4 Signposting to other services and support

In a number of cases the project support worker had been able to advise on additional services and support which the carers were unaware of. This included providing details for clubs and organisations such as the Pendrels Trust, Liaise (SEND Advice and Support in Lincolnshire), Carers First and Voice (to help with form filling) as well as suggesting additional support may be available from Social Services.

It did give us access to the care we needed. Support we needed. Things we needed. Like physiotherapy. And speech and language. Because this was suggested, I was then able to get in touch with the social worker as ask for speech and language (Carer 10)

Project support workers generally appeared to be knowledgeable about the services and resources they were talking about although in one case the carers mentioned that the project support worker had been unaware of the day centre their son was at and in another case the project support worker had suggested applying for benefits for which the carer was not eligible.

3.4 Benefits to carers of the support received

Carers generally talked positively about the support they had received and the majority were able to identify clear benefits. For some this was around simply receiving information they had been unaware of, some of which they had used to make future planning decisions or improve the support they currently received.

Not all carers could clearly articulate what they felt were the benefits of the project and two carers stated that they did not feel the project support worker's visits had made any difference to them. However, during the interview it appeared that both had undertaken some future planning which they had not thought about previously. One had organised an emergency response plan and the other had received information about a local care home which would be suitable for her son and she was interested in using, but had previously been unaware of.

3.4.1 Isolation

Some carers talked about the isolation they felt due to their caring role and the benefits of simply having someone to talk to during the project support worker's visits. In some cases this isolation was due to them being physically isolated in a rural location meaning they were unable to easily get to carers groups which may offer them support. However in other cases carers had previously had a good support network, but were now feeling socially isolated. For some this was because they were spending more time at home with their son or daughter - "*Sometimes you see the four walls till you are blue in the face*" - and in other cases it was because their social network was shrinking as their friends got older and had more "*problems of their own*". These carers who felt isolated all talked not only about the benefits of the future planning they had undertaken, but also about the benefits of simply having the project support worker to talk to and share their situation with.

Because I know there is somebody out there now basically. And I'm not on my own in all this because sometimes I just need a break and go out on my own. Some quality time. (Carer 8)

3.4.2 Future support

The majority of carers had kept contact details for the project support worker who had visited them and knew how to get hold of them if required. One carer had contacted the project support worker for additional support whilst others talked

about being able to contact them if needed. However, carers also appreciated that this was a time limited project with task focussed support being offered around future planning

I did contact her once or twice actually. I was having a difficult time with [son] with the centre and she was lovely. Then I did ring her again to thank her for everything. (Carer 8).

We've filled the forms in. We've made the plans. Ticked all the boxes. But it would be nice. I know it's her job and she's finished her job with me now. I do believe when she's said ring me at any time. But I don't like putting on people. (Carer 7)

3.4.3 Benefits of having a plan

Many carers talked about the benefits of having a contingency plan, or future care plan, in place which had given them peace of mind and made them feel more settled about the future.

Well we have learnt quite a lot. The will. The power of attorney. A bit more about care homes. Doing it now rather than later. Even though we are not planning on putting [son's name] in a care home and we'll do the best we can.....We've learnt a lot and it's given us a push. (Carer 4)

We now feel more settled. If anything happens to one or the other, we haven't got 'oh now what do we do'. It's all in place. (Carer 4)

I think I'm more at ease. I know now that I'm not forgotten. (Carer 11)

3.5 Links to Adult Care Services

All carers reported that their son or daughter had an Adult Social Care Practitioner who they saw at least once a year. Comments about these Practitioners were very generally very positive, however since their children had

reached adult hood the carers often had very little contact with the Practitioner. In some cases meetings between the cared for and their Social Care Practitioner took place in a day care setting and the parents were not present. The Social Care Practitioner was also focussed on the needs of the cared for rather than any needs of the carers and in the majority of cases there had been no discussion around planning for the future.

The majority of carers welcomed the fact that this service was separate to Adult Care Services. They felt that they were able to be more open with the project support worker who was from an independent organisation and weren't being judged about their responses and situation. They also saw the project support worker as an advocate who was able to speak openly on their behalf and not be constrained by Adult Care Service policies and procedures. In one case the carer also had the perception that the project support worker had more time to spend with them than a Social Care Practitioner would have done.

You are more open. And you talk in a different way. It was a very easy conversation all the time. It wasn't all like question and answer. It was all done in a conversation which was free of pressure. (Carer 5)

I felt confident that whatever I said good, bad or indifferent was not going to be put down against me. (Carer 7)

Definitely because social services are so handicapped. They have set policies. Whereas with carers it's carers for carers. Which makes a big difference because they understand more what carers need so that makes a big difference. (Carer 10)

4.0 Discussion

4.1 Limitations of the evaluation

Over 90 carers took part in the Older Carers Project, although at the time of the evaluation, only 24 of these were happy for their details to be passed to the University of Lincoln to be part of the evaluation. These numbers, along with limited resources, meant the study was restricted to a small sample size for face to face interviews.

The names of participants were provided by the Lincolnshire Carers and Young Carers Partnership and all had completed the project. The views of those people who did not wish to take part in the project, or who did not complete the project are therefore not included, nor are the views of any of the project support workers involved. This may mean that the people involved are those who were keen to develop plans for the future (in some cases they had already started this) rather than those who are having more difficulty thinking about the future.

4.2 Discussion and recommendations

Very few of the carers interviewed had previously considered making plans for the future and where they had there was a large reliance on other family members to take on the caring role. A number of carers talked about their concerns regarding what would happen to their son or daughter should an emergency arise and yet few had any plans in place for such an eventuality prior to this project. Since talking to the project support worker the majority of carers had put contingency and future plans in place and talked about how they now had peace of mind about what would happen to their son or daughter in the future. The project had therefore certainly achieved its aim of helping carers put such contingency plans or future care plans in place, or updating plans they had already made.

4.2.1 Recruiting carers to the project

It was clear from talking to carers that very few of them had the time to be proactive about finding resources, or didn't want to ask for help. In most cases carers therefore needed to be asked to be involved with, or referred directly, into a project such as this. It is not known what proportion of carers who were contacted declined to take part in the project, or their reasons for making this choice.

A number of carers who did get involved reported that they had initially received a letter and phone call about the project. Copies of the letter and Frequently Asked Questions Sheet which LCYCP had developed in consultation with County Carers and LCC are included in Appendix 4. These letters were followed up with a phone call a week later to further explain the project and sign carers up. Despite this contact by letter and telephone call a number of carers still stated that they were unsure exactly what the project was offering them when they agreed to take part. This may be due to carers not having time to read the information they received in detail or the fact that they had not received support like this before so did not know what to expect. However, it is imperative to make sure that the aims and benefits of the project are clearly and concisely explained to carers so that they can make a well informed decision about whether they would like to be involved.

It was also noted that there was sometimes a gap between carers signing up the project and a project support worker being able to visit them so carers may have forgotten during this period what the project was focussed on.

Recommendations

The evidence collected during this independent evaluation demonstrates there is a clear need for a continued service which is proactive in supporting carers around the issue of long term planning.

Provide a service which is proactive in contacting carers and liaises closely with organisations supporting carers, such as Carers First, as well as other health

care providers such as GPs, pharmacists, optometrists, social care practitioners etc.

Ensure information provided during the initial contact with carers clearly articulates the aims of the project and the benefits of taking part and that any visit from a project support worker is undertaken as soon as possible after the initial contact has been made.

4.2.2 Caring for the carer

Carers valued a service that was focussed on them rather than the cared for person and none were aware of any other services that offered support such as this nor had they been offered any support aimed directed at themselves. Whilst their children were under 18 they had had close contact with a Children's Services Social Worker, but in many cases this had now ceased as the son or daughter now saw their Adult Social Care Practitioner alone.

Recommendation

There is a need for a service which offers help and support focussed on the carers of children with learning disabilities, particularly during their discharge from Children's Services and transition to Adult Social Services.

4.2.3 Age of the carer and cared for

Although all of the carers were considered to be 'older carers' their ages spanned almost 20 years and the age of those cared for spanned 30 years from 22 to 52. These individuals, as well as their parents were therefore often at different life stages. In some cases the son or daughter were just leaving formal education whilst in other cases parents were changing life stage as they had recently retired. The needs of these groups may vary and it may therefore be necessary to think about future planning for carers according to the life stage that their family is at rather than simply the age of the parent. Some of the younger parents also appeared to find it easier to talk about the future for their son or daughter. This may have been due to their son or daughter being younger and at a different

life stage, for example leaving education, rather than the discussions with older parents centering around their own mortality. This may highlight the need to think about future planning with younger parents so that they have time to begin planning long term options.

Recommendation

Consider offering future planning support to younger parents or tailoring support for those at different developmental life stages.

4.2.4 Flexibility of support

For the majority of carers the flexibility of the project with regards to when visits took place and how long they lasted was very important. Some carers required a considerable degree of emotional support and required longer visits, whilst other carers were far more task focussed and needed shorter, but more regular visits, to discuss decisions they had made about their future planning and be given instruction about the next step. Despite carers receiving very different amounts of support with regards to time there were no complaints that they had not received enough support to achieve the aims of producing future plans.

Recommendation

Continue to ensure that project support workers can be flexible with respect to the length of time of visits and the length of time between visits.

4.2.5 Role and knowledge of the project support worker

Although the project was centred around future planning the project support workers were able to offer a holistic counselling type approach which worked well with older carers. This gave them the opportunity to build up trust and understanding with the carer and offer support around a range of subject matters, not just about future planning. In order to achieve this it is vital that project support workers are able to listen and be non-judgemental, as well as being knowledgeable about all of the services available.

A number of carers had been informed about future options they were unaware of or had now been able to access additional services or benefits. It is likely that a number of these, such as discussing different housing options or legal planning will help families prevent a crisis happening in the future. In a few cases the project support worker had suggested additional benefits or services which the carer was then not eligible for. Although there were no complaints about this from the carers it is important that project support workers are knowledgeable so as not to raise expectations or waste the time of carers.

Carers highlighted that in some cases the project support workers themselves were carers which enabled them to empathise with their situation. They welcomed this opportunity to share their experiences with someone who may be in a similar position and offering other opportunities through carers meetings or workshops may be required.

Recommendations

Ensure project support workers are knowledgeable about the local services on offer and whether individuals may be entitled to additional support.

Provide opportunities for carers to share their experiences and knowledge with other carers. In some cases this may be possible by recruiting project support workers who are carers, but where not possible this highlights a need for organising more opportunities for carers to meet and discuss issues with others in a similar situation, for example through carers workshops or meetings.

4.2.6 Continuous care and support

Due to the nature of funding available the Older Carers Project was time limited and although project support workers had passed on their contact details it is likely that these will expire when the project finishes. Although the funded period enabled all carers to receive enough support to put contingency and future care plans in place a number of carers stated that they were disappointed that the project had come to an end.

As discussed above some of these carers were isolated either geographically or socially and simply valued the support of knowing they could phone someone if needed. However others stated they were used to doing things on their own and it is likely that they wouldn't proactively contact the project support worker despite the fact that they valued their support or may need to update their plans in the future. It would therefore be beneficial if a project such as this could have a longer lifespan. This would enable project support workers to contact carers on a more regular basis (once a quarter for example), to check they are OK or offer more up-to-date timely information about a range of other topic areas, both emotional and practical, in addition to future and emergency planning.

Recommendation

Consider a more permanent service so that those caring for sons or daughters with learning disabilities could be supported over a longer period of time and offered tailored support on a range of issues.

4.2.7 Sharing plans

A number of carers were unsure who their future care plans had been shared with beyond the project support worker. For carers to have full confidence that their plans will be carried out it is important that project support workers provide clear information about where the plans are stored, who has access to them and how they will be implemented when required. Other carers talked about their plans, but in some cases, particularly where family members were mentioned as taking on a caring role they had not shared the plan with those family members. Project support workers therefore need to advise carers to share their plans with relevant family members, or other named individuals, so they know what the plan is, or where it is stored for when it is required. If possible this may take place by inviting the named people to one of the project support worker's meetings.

Recommendations

Ensure that carers are fully aware of where their future plans are stored. Project support workers should also make sure, where possible, that plans are shared

with any other named individuals either by having a face to face meeting with them or sending them a paper copy of the plan.

4.2.8 Delivery by a third sector organisation

The majority of carers no longer had any direct contact with Adult Care Services and felt that this project was better run separately by a third party organisation such as LCYCP. As discussed above they felt that an independent project support worker would be less judgemental about their ability to provide care and would be more able to advocate for them in all situations, including discussions with Adult Care Services. It is important that carers have this confidence in the project support worker so that they are able to talk openly about their plans for the future. However, whichever organisation the project support worker is employed by it is important that they maintain links with Adult Care Services so that the two services complement each other.

Recommendation

Continue to plan and deliver a project such as this by a third sector organisation if possible, but ensure close links with Adult Care Services remain.

4.2.9 Meeting the person cared for

In most cases, carers reported that their project support worker had met the person cared for although the person for whom the future plans were being put in place was not involved in the discussion. It has been noted already that carers appreciated very much that the project support worker's focus was on them and many of the topics discussed were complex and sensitive: for instance, funding mechanisms for future care and the death of their parent and main care-giver. Nevertheless, the wishes of the person cared for are often an important factor in future planning. To assist towards achieving this this LCYCP offered the opportunity for those being cared for to take part in circles of support. This helps support those with learning difficulties to realise their dreams and aspirations and would help to inform the discussion around future care plans. Carers also gave a high value to continuity for their son or daughter, whether this meant safeguarding their right to remain in the family home or taking account of strong

existing relationships with paid or family carers.

Recommendation

The project support worker should always be introduced to the person for whom the plan is being made and they should record how the wishes of the person cared for have been taken into account. An opportunity should be offered within the documentation for carers to identify support needed by the person cared for to be involved in planning for their future and to gain more information about the options available to them. This might include circles of support, advocacy, befriending or experience of alternative care.

4.3 Conclusions

This process evaluation gave carers who had been part of the Older Carers Project the opportunity to talk about their experience of the intervention and time they had spent with the project support worker, as well as highlighting the overall benefits of being involved. The value of this approach is that, in addition to helping to determine whether a service should continue, it can also use the views of carers to shape and inform the design of any further services. This should help to ensure that future projects are acceptable to future recipients as well as meeting their needs.

Overall the evaluation found that the Older Carers Project had been a very successful project in helping carers set up emergency and future plans. The participants all held the support they had received from project support workers in high regard and valued their knowledge and flexibility. Carers had never been offered any support aimed at themselves and in some cases it had enabled them to obtain benefits and support that they did not know they were entitled to. The preparation of both contingency and future care plans had enabled some carers to feel more settled and positive about the future for both themselves and their disabled son or daughter.

Appendix 1: Ethics application and approval letter`

**EA2
Ethical Approval Form:
Human Research Projects**



This form must be completed for each piece of research activity whether conducted by academic staff, research staff, graduate students or undergraduates. The completed form must be approved by the designated authority within the Faculty.

Please complete all sections. If a section is not applicable, write N/A.

1 Name of Applicant	Dr Ros Kane
	Department: School of Health and Social Care
2 Position in the University	Principal Lecturer
3 Role in relation to this research	Principal Investigator
4 Brief statement of main Research Question	<p>To what extent do carers feel there has been an improvement in their circumstances as a result of being involved with the Older Carers Project?</p> <p><u>Project Title:</u> Evaluation of the LCYCP (Lincolnshire Carers and Young Carers Partnership) Older Carers Project</p> <p><u>Project outcomes:</u> Qualitative interviews documenting the views and experiences of carers in receipt of the intervention</p> <p>Recommendations to LCYCP to inform the direction and delivery of future services.</p> <p><u>Project outputs</u> The primary output will be a report submitted to LCYCP offering an impartial evaluation of the project.</p>

5 Brief Description of Project

Background

Carer and family support arrangements for people with learning disabilities are at risk of breaking down over time as the principal carer ages and the needs of the carer and cared for increase. Without additional support these pressures can ultimately lead to increases in maintenance costs through unplanned and unwanted residential care and hospital admissions.

A majority of carers over the age of 70 who are caring for people with a learning disability have chronic illness or a disability, health problems which are exacerbated by a lack of appropriate respite care and/or reluctance on the part of the carer to access respite where it is available.

Carers and their families are often socially isolated because of the constraints imposed by the caring role and the carer and person being cared for may have developed a mutually dependent caring relationship.

In acknowledgement of the particular difficulties facing this group and the risk of carer breakdown, Lincolnshire County Council (LCC) has secured funding from the Better Care Fund (BCF) for targeted project work with older carers.

The Older Carers Project is looking at how LCC supports carers over 70 who are looking after someone with a learning disability in their home. The project is taking a holistic approach looking at the whole family and wider support network. It is also looking at putting carers assessments and emergency plans in place and talking about planning for the future.

The aim of the project is to:

- Ensure older carers are known to LCC to maintain their mental and physical health and wellbeing and thereby continue in their caring role.
- Alleviate or delay a breakdown in caring relationships and lessening the need for or risk of increased social care maintenance services or health services.

Phase 1 of the project has been carried out by LCYCP. It has involved interviewing 12 carers and asking them about their caring role as well as 8 interviews with key stakeholders from the following organisations (LCC, County Carers, LCYCP, Age UK, Carers Team).

The University of Lincoln is being engaged in Phase 2 to independently assess whether carers feel there has been an improvement in their circumstances due to being involved with the project.

Time frame

June 2015: Applying for University ethics/ Lincolnshire Adult Care Research Governance approval.

July 2015: Review relevant literature on carer interventions.

July/August 2015: Liaise with LCYCP to obtain project updates and begin organising interviews.

September 2015: Collection of interview data.

October 2015: Transcription and analysis of interview data.

November 2015: Report writing.

Methodology

The study will apply qualitative research methods utilising in-depth interviews to best accommodate older carers. 10-12 interviews will be carried out with those in receipt of the intervention in a convenient location, e.g. their home. This is an appropriate method to explore the views of this particular group as they provide both privacy and space.

Participants will be invited via the Older Carers Project team (who have an established relationship with potential participants) on behalf of the University research team. In addition to this the Older Carers Project team will take responsibility for organising the interviews with potential participants.

Interviews will be digitally tape-recorded (with permission) and transcribed verbatim.

Data analysis and interpretation: The established framework method of qualitative analysis will be used (Ritchie and Spence 1994). NVIVO will be utilised to process data.

Report writing: The results from the evaluation will be written into a final report and submitted to LCYCP to inform future service direction and delivery.

	Approximate Start Date: June 2015	Approximate End Date: November 2015
6 Name of Principal Investigator or Supervisor	Dr Ros Kane	
	Email address: rkane@lincoln.ac.uk	Telephone: 01522 837326
7 Names of other researchers or student investigators involved	David Nelson, Research Assistant, School of Health & Social Care Paul Mansfield, Senior Lecturer, School of Health & Social Care Helen Davies, Senior Lecturer, School of Health & Social Care	
8 Location(s) at which project is to be carried out	Participant's home or yet to be confirmed community location	
9 Statement of the ethical issues involved and how they are to be addressed – including a risk assessment of the project based on the vulnerability of participants, the extent to which it is likely to be harmful and whether there will be significant discomfort. (This will normally cover such issues as whether the risks/adverse effects associated with the project have been dealt with and whether the benefits of research outweigh the risks)	The Ethical issues for this study which have been considered are as follows: Confidentiality of data/information and interview process: Regarding the qualitative data collection, participants will take part on a completely voluntary basis, it will be made clear that they can withdraw at any stage of the process should they wish and to decline to answer any specific questions. The participants will be required to give informed consent prior to the interview process beginning following the reading of the information sheet. It is estimated that the interviews will last 45-60 minutes, and participants will be informed that they may terminate the interview earlier, or withdraw should they feel uncomfortable at any point. Time will be allowed both prior and post interview for any questions to be asked and answered. Great effort will also be made to reassure the participants that strict confidentiality will be upheld throughout the research process and specifically all data that are collected by the research team will be made anonymous prior to the interviews being analysed and reported on. This method should ensure that participants feel able to answer honestly and openly during the interviews, assured that anonymity and confidentiality will be maintained throughout the research process. All data relating to the fieldwork will be stored in a locked metal filing cabinet and on a password protected PC at the University of Lincoln, Brayford Campus. Only the immediate research team will have access to the participants' personal data.	
10 Does this research require the approval of an external body?	It is evaluation so does not require NHS REC/R&D approval – but approval will be sought from the Lincolnshire Adult Care, Research Governance Panel.	
	If "Yes", please state which body: Lincolnshire Adult Care	
11 Has ethical approval already been obtained from that body?	Yes <input type="checkbox"/> -Please append documentary evidence to this form. No	
	If "No", please state why not:- In the process of applying for approval Please see notes in section 10 above.	

Please note that any such approvals must be obtained and documented before the project begins.

APPLICANT SIGNATURE

I hereby request ethical approval for the research as described above.
I certify that I have read the University's ETHICAL PRINCIPLES FOR CONDUCTING RESEARCH WITH HUMANS AND OTHER ANIMALS.



Applicant Signature

Date 28/05/15

_Ros Kane

Applicant Name

**FOR STUDENT APPLICATIONS ONLY –
Academic Support for Ethics**

Academic support should be sought prior to submitting this form to the Faculty Research Ethics Committee.

- Undergraduate / Postgraduate Taught application Academic Member of staff nominated by the School/Department (consult your project tutor)
- Postgraduate Research Application Director of Studies

I support the application for ethical approval

Academic / Director of Studies Signature

Date

PRINT NAME

FOR COMPLETION BY THE FACULTY RESEARCH ETHICS COMMITTEE

Please select ONE of A, B, C or D below:

A. The Faculty Research Ethics Committee gives ethical approval to this research.

10 Please state the condition (inc. date by which condition must be satisfied if applicable)

B. The Faculty Research Ethics Committee gives conditional ethical approval to this research.

C. The Faculty Research Ethics Committee cannot give ethical approval to this research but refers the application to the University Research Ethics Committee for higher level consideration.

11 Please state the reason

D. The Faculty Research Ethics Committee cannot give ethical approval to this research and recommends that the research should not proceed.

12 Please state the reason, bearing in mind the University's ethical framework, including the primary concern for Academic Freedom.

Signature of the Chair of the Faculty Research Ethics Committee

Signature

Date



School of Health and Social Care Ethics Committee
College of Social Science
Bridge House
Brayford Pool
Lincoln
LN6 7TS

Telephone 01522 882000
18 June 2015

RE: To what extent do carers feel there has been an improvement in their circumstances as a result of being involved with the Older Carers Project?

Dear Dr Ros Kane.

Thank you for your application to the 2015-06-17 School of Health and Social Care Ethics Committee.

The Committee would like you to include a short statement on the consent form regarding the complaints procedure, as follows:

If you are not happy about the way the evaluation/research has been conducted please contact the Chair of the School of Health and Social Care Ethics Committee:

Address:
Dr Zowie Davy
School of Health and Social Care
University of Lincoln
Lincoln
LN67TS
Email:
zdavy@lincoln.ac.uk
Tel No.
01522837748

Following these insertions, and on the basis of what is stated in the EA2 form, the Ethics Committee are happy for you to commence your research for the study above.

On behalf of the Ethics Committee I would like to wish you well with the research.

Appendix 2: Interview topic guide

- Thanks, introductions, practicalities (privacy, timings, independence from services, confidentiality)

- Talk through PIS

- Opener – can you set the scene / tell us a bit about your situation?
 - Relationship
 - Start and duration of caring
 - Ages of carers and person cared for – early/mid/late
 - Health of carer

- Background to the project
 - Can you tell me about the project? Your understanding of it?
 - How did you come to be using the project?
 - How did you hear about it?
 - Why did you decide to take part?
 - What did you expect from the project when you first heard about it?
 - Had you come across a service like this before? How was it different?

- Experience of the project (talking about the project journey)
 - Who visited as part of the project?
 - How many times? How long for?
 - Did they meet the person cared for?
 - What sort of things did you talk about?
 - Thinking back to before these visits, where were you with these issues?
 - How are things different now compared to when you first started using the service? Can you give me some examples?
 - Did they help you to access any services or resources?
 - Did they help you to plan for the future? How?
 - How do you feel about the service?

- Outcome of the process
 - How has the service helped you? If it hasn't that's fine!
 - What has made the biggest difference?
 - What may have happened without that support?
 - What is the plan that came out of your discussions?
 - Who knows about the plan? (Other family members? Professionals? Person cared for?)
 - Do you have a social worker? How are they involved? (Generally? Specifically with planning for the future?)

- Evaluating the process
 - What did you expect from the project? May have discussed!
 - You mentioned earlier you expected ***** from the project, did it fit your expectations? How?
 - What is different for you as a result of (name of project support worker)'s visits?
 - Is there anything you think could have been done better?
 - Did it make a difference that (name of project support worker) was from the carers project and not from social services
 - Is there anything else that you think is important for us to feed back?

- Further help
 - Who would you contact for further help with the issues we have discussed?
 - Carers' workshops
 - How learning from the project will be shared to benefit other carers

Can you just summarise what the project has meant to you and any difference it has made?

Appendix 3: Participant information sheet and consent form



Participant Information Sheet

Evaluation of the LCYCP (Lincolnshire Carers and Young Carers Partnership) Older Carers Project

We would like to invite you to take part in our evaluation study. Before you decide we would like you to understand why the work is being done and what it would involve for you. One of our team will go through this information sheet with you and answer any questions you have.

This study is being funded by Lincolnshire County Council. The study has been reviewed internally by an expert advisory group within the College of Social Science at the University of Lincoln, as well as externally, by the Lincolnshire Adult Care Research Governance Panel.

You are being invited to take part in an individual interview. During the interview you will be asked to talk about your experiences of the Older Carers Project.

What is the purpose of the study?

We would like to examine the views of carers in receipt of the Older Carers Project.

Why have I been invited?

You have been invited because of your involvement and experience of the Older Carers Project.

Do I have to take part?

Participation is entirely voluntary. If you agree to take part, we will ask you to read and complete the consent form.

You remain free to withdraw at any time, without giving a reason. Withdrawal from this study will not affect the support you currently receive in any way. However, if you decide to withdraw, the information you have provided up to the point of withdrawal may still be used in the research.

What will happen to me if I take part?

You will be invited to attend one interview which will last approximately 45-60 minutes. It will take place in a private and convenient location with one researcher. If you do not wish to answer any of the questions then you do not have to.

With your permission the interview will be digitally recorded and typed up.

PIS: Older Carers Project
Version 1.0
Date: 19/05/15



Will my contribution to the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you, or that you choose to share, will be anonymised and handled in confidence.

All recordings will be made using digital media files and transcription will also be held on electronic files. All files will be held on an encrypted computer for seven years and then destroyed.

What will happen to the results?

The results of the study will take the form of a written report to the funders which will also be widely disseminated using the University of Lincoln Research Repository.

Participants will be kept fully informed of any final outputs from the research and will be offered the opportunity to receive a copy of the final report.

What if I have complaint or concern?

If you have any questions about any aspects of this study, please speak to the principal investigator who will do their best to answer your questions. Details are below:

Dr Ros Kane
Principal Lecturer
University of Lincoln
School of Health & Social Care
Brayford Pool
Lincoln
LN6 7TS

T: 01522 837326
E: rkane@lincoln.ac.uk

PIS: Older Carers Project
Version 1.0
Date: 19/05/15



UNIVERSITY OF
LINCOLN

Evaluation of the LCYCP Older Carers Project
PARTICIPANT CONSENT FORM

Please tick box

1. I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my current support being affected.
3. I understand that all the information I give will be STRICTLY CONFIDENTIAL.
4. I understand that the results from this study will only be presented in anonymous form.
5. I agree to the interview being tape-recorded and transcribed.
6. I agree to take part in this study.

Signature (participant): _____ (please sign)

Print Name: _____

Date: _____

Signature (researcher): _____ (please sign)

Date: _____

If you are not happy about the way the evaluation/research has been conducted please contact the Chair of the School of Health and Social Care Ethics Committee:

Address:
Dr Zowie Davy
School of Health and Social Care
University of Lincoln
Lincoln
LN67TS
Email: zdavy@lincoln.ac.uk
Tel No. 01522837748

Consent: Older Carers Project
Version 1.0
Date: 19/05/15

Appendix 4: Letter and Frequently Asked Questions Sheet used by LCYCP to introduce the project to carers



Carers together, a voice for change.

Lincolnshire Carers & Young Carers Partnership
Commerce House
Outer Circle Road
Lincoln LN2 4HY
Tel: (01522) 846911
mariecottam@lincscarerspartnership.net

2016

I am writing to tell you about a project which Lincolnshire County Council have asked the Lincolnshire Carers and Young Carers Partnership (LCYCP) and County Carers to help with.

The Council is aware that many family carers of a person with a learning disability are often deeply concerned about how their loved one will be looked after in the future; perhaps when they themselves are unable to continue as the main carer.

The project is aimed at giving carers the chance to discuss their caring role with someone who understands and takes the time to listen. It is about offering carers peace of mind when thinking about future caring arrangements; knowing that their concerns and wishes have been discussed and listened to.

As a carer who might find the project beneficial, we would like to arrange an appointment for one of our Project Support Workers, to visit you at home, at a time convenient to you. Our Project Support Workers are easy to talk to and are very understanding.

Marie Cottam from LCYCP will contact you over the coming weeks to see if you would like to take part in the Project. The help we offer is free and completely independent of Lincolnshire County Council.

Included with this letter is additional information about the project. If you have any questions or would like to speak to myself or Marie Cottam about any aspect of the project please call us on 01522 846911 or email; mariecottam@lincscarerspartnership.net If you do not wish to take part in the project, please contact Marie, or leave a message on the above number, and we will delete your details accordingly.

We look forward to speaking to you in due course.

Yours sincerely

Philip Burgess
Project Lead
Lincolnshire Carers and Young Carers Partnership

Registered Charity No: 1164639



Questions and Answers – May 2016

Why have I been sent a letter?

Lincolnshire County Council have asked Lincolnshire Carers and Young Carers Partnership working with County Carers to contact people such as yourself who have been caring for a family member with a learning disability for many years and might not be getting all the help they may be entitled to.

The project is completely independent of Lincolnshire County Council. The project is all about listening to you as a Carer, looking at what is working and what is not working for you in your caring role and working on a future caring plan.

Your son or daughter's social worker will be aware that we have contacted you.

How do I check that this is a genuine communication?

Telephone Lincolnshire Carers and Young Carers Partnership on 01522 846911.

Website: www.lincolnshire.gov.uk/lcycp

Email info@lincscarerspartnership.net

Telephone Lincolnshire County Council 01522 552222 and ask for Mick Skipworth.

Who is promoting the Project?

Lincolnshire Carers and Young Carers Partnership working with County Carers Learning Disabilities Lincolnshire.

How might this project help me?

One of the really good things about this project is that our Project Support Workers will be able to visit you at home, at a time and date convenient to you. They can chat to you about how you find your caring role and they will be able to work with you, perhaps over several visits setting up a futures care plan. They can also explain how some simple arrangements can be put in place to make sure the person you care for is kept safe, if for any reason, you are unable to care for them.

How long will the visit take?

The visits will last for as long as you are comfortable to continue and you feel it is beneficial. The number of visits will depend on what support you need with the future caring plan.

Lincolnshire Carers & Young Carers Partnership, Commerce House, Outer Circle Road, Lincoln LN2 4HY Tel: (01522) 846911 mariecottam@lincscarerspartnership.net

What happens if I am no longer a carer?

Please telephone 01522 846911, ask for Marie Cottam or leave a message with one of her colleagues to advise and your details will be removed immediately from our database.

What will happen if I do not wish to take part in this Project?

There is no obligation to take part in this Project. Please telephone 01522 846911, ask for Marie Cottam, or leave a message with one of her colleagues to advise that you do not wish to take part. It would be appreciated if you could give a reason why, but should you not wish to, we will still remove your details from our database immediately.

What happens if I agree to take part and then half way through I no longer wish to continue?

Obviously we would like you to stay part of the Project in order for us to help you with your future caring plan. There is no pressure on you to continue, but it would be appreciated if you could contact Marie Cottam to explain why in order for us to understand whether we could have done something better to help you stay part of the Project. However, we will ultimately respect your decision and your details will be removed from our database.

How does LCC/LCYCP use my personal details?

Your personal details will be kept confidential and will be destroyed at the end of the Project. We do not share your information with third parties.

Are you selling services or products?

Please be assured, we do not sell services or products. Our Project Support Workers are able to advise on particular services which may be available, but you will ultimately make the decisions on which services you wish to use, our Project is about the choices available to you.

Will I be charged for anything?

There is no charge to take part in this Project.

Will you want to know about my savings?

No. There is no reason for us to ask you about any savings you, or your family have.

Will I be part of a mailing list?

No.

Lincolnshire Carers & Young Carers Partnership, Commerce House, Outer Circle Road, Lincoln LN2 4HY Tel: (01522) 846911 mariecottam@lincs-carers-partnership.net



UNIVERSITY OF LINCOLN

University of Lincoln
Brayford Pool
Lincoln
LN6 7TS

Telephone: +44 (0)1522 886644
Fax: +44 (0)1522 886974
Email: enquiries@lincoln.ac.uk
www.lincoln.ac.uk