



Final Evaluation of Comic Relief funded
Changing Scenes, Oxfordshire Family
Support Network's project to support
older carers of people with learning
disabilities. June 2015

Changing Scenes

Final Evaluation

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Changing Scenes: Final Evaluation

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Executive Summary

Changing Scenes was funded for 3 years 2012-2015 to develop a model of support for older carers in a rural area.

It has operated at a time of unprecedented change in the learning disability context with reform to Welfare Benefits and Local Authority budget cuts both impacting upon this vulnerable group, older carers.

Changing Scenes has met or exceeded its aims

- ✚ Over 100 carers have accessed the project
- ✚ 4 local carer support groups are established
- ✚ The project has made the voice of older carers louder in Oxfordshire. It has influenced, and is continuing to influence local policy. Carers have a seat at the table.
- ✚ There are many examples of carers engaging more effectively with statutory services to plan for the future of their relatives as a result of support from the project
- ✚ The project has enabled Oxfordshire Family Support Network to leverage considerable additional funding, from a range of sources, to support older carers locally, and has spawned other projects including a HealthWatch funded Report into the needs and experiences of carers of people with significant problems; an ESF funded Creating Family Champions course; an initiative to set up Safe Places in the county; and an Oxfordshire County Council funded Quality Checkers programme.
- ✚ The project has gained a national reputation through presentations at Conferences, and through contributing to research on the experiences of carers of people with autism, mental health problems and challenging behaviour.

Lessons from the Project are that:

- ✚ There is a pressing need for support for carers at a time of major upheaval in service provision and in benefits, which statutory services do not meet
- ✚ Projects such as this deliver results
- ✚ Carers engage in a range of ways, not solely through local groups
- ✚ Most carers value face to face personalised contact, augmented by information and advice delivered through IT
- ✚ It takes time to build momentum as there is no register of older carers in the area, so contact is largely through personal recommendation from other carers and professionals
- ✚ Building carers' confidence to plan for the future also takes time, but it has concrete outcomes
- ✚ Professionals value the project highly as they are aware that they lack the time to support older carers effectively; and they can have difficulty letting carers know what is available.
- ✚ Older carers are unlikely to want to run local groups, as many have health problems of their own, and have had a lifetime of caring. Finding carers who will be willing to support others means extending the age range and including siblings as well as parents

Recommendations

It is recommended that to gain the maximum value from Comic Relief's investment to date that the project continues, with an emphasis on:

- ✚ Building sustainability through training younger family members to facilitate groups
- ✚ Extending the age range to carers over 50, and younger family members (usually siblings)
- ✚ Building a register of older carers to enable the Local Authority to plan for the future
- ✚ Extending the geographical reach of the project into areas hitherto untouched by it
- ✚ Documenting the impact of austerity on older carers through gathering evidence from them
- ✚ Working closely with professionals to ensure that they can reach older carers and to maximise referrals to the project

Introduction

The Oxfordshire Family Support Network's (OxFSN) Changing Scenes Project for older carers of people with learning disabilities was funded by Comic Relief from June 2012 to June 2015. This evaluation seeks to summarise the achievements of the project at the end of its 3 year life, and to make some recommendations for the future.

The purpose of Changing Scenes was to develop innovative ways to support older carers (over 60) with sons and daughters with a learning disability living in rural areas. Its method of doing this has been primarily through recruiting older carers to local support groups facilitated by the Oxfordshire Family Support Network project worker. The aim of these groups is to provide information and support, to promote social connectedness and to build participants' confidence.

The project has the following intended outcomes:

- ✚ The project will reach a minimum of 40 older carers in its first year, and between 100 and 150 by the end of 3 years
- ✚ Older carers will have the confidence to start local informal groups
- ✚ Older carers will influence the strategic thinking of the local authority and clinical commissioning groups on need for planning to support older carers, and to make provision locally for their sons and daughters when they can no longer care
- ✚ Older carers will be better informed about their entitlements, those of their sons and daughters, and will know how to access local sources of support, information and advice
- ✚ Older carers will develop supportive relationships with others in their situation

Learning

The anticipated learning from the project is:

- The best model for working in a rural county to deliver support to older family carers
- A model of planning and support that is **holistic** for the family and which enables health and social care to work in an integrated way
- How resources and information can be delivered in a way that reaches the target audience most effectively, as many are not able to utilise digital technology. This may involve partnership working with other organisations delivering training on the use of technology
- The most effective way to mentor and support older carers to run peer to peer support groups
- Understanding the barriers to carers making plans for the future and building effective support around them

At the time of the mid term Evaluation (autumn 2014) my conclusion was:

Changing Scenes has made a considerable impact, is currently well on the way to achieving its outcomes, and in some respects, going beyond them

The Context

Changing Scenes operated at a time when it was widely argued that cuts to Local Authority budgets and welfare reform would disproportionately hit disabled people. In 2013, The Centre for Welfare Reform estimated that cuts to Local Authority budgets and Welfare benefit changes taken together would cost each disabled person over £4000 per annum

<http://www.centreforwelfarereform.org/uploads/attachment/354/a-fair-society.pdf>.

In each of the two preceding Evaluations, I made the point that this project was particularly timely given the impact of three significant policy directions:

- Austerity - cuts to Local Authority Budgets
- Welfare benefit reform, particularly the change from Disability Living Allowance to Personal Independent Payment
- Personalisation of services, the expectation that over time all users of social care services will hold the budget for their services.

If anything, the impact of these three policy directions is even more significant in 2015.

Changing Scenes has sought to support older carers to manage the impact of these changes, and to ensure that they are minimised.

The impact of Austerity

The Local Authority's Big Plan (2012-2015) sets out broad principles for the future, though detail is lacking. It scopes an annual budget increase of £2.1m to meet increased demand for learning disability services due to demographic change, but notes that demand is increasing at a higher rate. At the same time, it is expected to achieve efficiency savings of between £5 and £6 million per annum, and claw back the £4m overspend recorded at the end of 2014. The impact of austerity is likely to be greatest on those adults who continue to live with family, the people Changing Scenes is targeted at, as costs for people in Care Homes and Supported Living are relatively inelastic. We are talking here about a sub set of the estimated 11,100 adults in Oxon. There are no statistics for the number of adults with learning disabilities living with family carers over 60. However, the Big Plan states that 2,066 people (18%) are supported by the social care learning disability team which may mean they live with family. Of these 1,794 (16%) receive a paid for service. It is likely that people living with older carers are included in this group.¹

The need to make savings in Local Authority Budgets is having a significant impact on older carers in Oxfordshire. In research interviews for both the mid term (2014) and this final evaluation families

¹ Of the rest:

282 live in a care home, of whom 190 are out of county

659 are in Supported Living

469 get a Direct Payment

82 get home care

reported that they had fleeting relationships with care managers, that interventions were short term, and that services are only reactive to crises, not proactive.

At the time of this Evaluation (May/ June 2015) the Local Authority were implementing 'Fairer Charging', which entailed a reassessment of how much people are expected to contribute to the cost of the services they receive. This is discussed further in the Report findings.

Further change is likely to impact on older carers. The 'Big Plan' 2015 – 2018 sets out in broad terms the means by which OCC will meet its efficiency targets. The Council is required to save 5.84% annually on its learning disability budget, over 4 years. The emphasis in the Big Plan is reductions in specialist learning disability teams in favour of people using mainstream services, including health services. Some commentators have expressed concern that these changes would result in the loss of Local Authority Day Services. Increased Choice and Control, the Big Plan's espoused principle, may mean that fewer people opt for traditional day services, making them financially unsustainable. Yet these are services on which many older carers rely.

All those supported by Local Authority Social Care Teams will be reassessed on their need for support during the year 2015-2016. This reassessment will determine what services they receive. It is vitally important that carers understand the implications of the assessment, and are supported to complete the process to ensure a favourable outcome.

Meeting the Winterbourne View Concordat Pledge

190 (67%) of the 282 Oxfordshire people living in learning disability care homes are placed outside the county. This high reliance on out of county placements potentially has a significant impact on older carers as it indicates that unless they make provision for their relatives before they die or become unable to care, their relative is likely to be placed away from familiar people and places. Bill Mumford, then Director of the National Winterbourne View Joint Improvement Programme, was of the view that to meet the Winterbourne View pledge it is important to

Seek to build up expertise and support families effectively before it all goes wrong (quoted in HealthWatch Oxfordshire and OxFSN 2014 p.27)

There is little evidence that the hard pressed statutory services are in a position to do this, given the need to reconfigure services to make savings. However, the Changing Scenes Project does this for the families with which it is in contact.

Uncertainty over NHS Provision

There has been a loss of confidence in local specialist NHS services run by Southern Health, due in part to the untimely deaths of two young men from Oxfordshire whilst in the care of Southern Health, in 2012 and 2013. The OCCG is currently reviewing its contract with Southern Health. This has cast a shadow over the future of local NHS provision and cut across joint working between health and social care. The impact of this uncertainty on local families, particularly those supporting people with autism, mental health problems and / or challenging behaviour is documented in the Report commissioned by HealthWatch from OxFSN, *A Local Experience of National Concern (2014)*, and impacts either actually or potentially on carers supported by Changing Scenes.

Personalisation

The 2014 Care Act reiterated the Government's commitment to enabling all people receiving social care services to maximise their choice and control by holding their own budget to purchase services of their choice. This is a direction of travel dating from the early 2000s.

It has considerable significance for older carers who are faced with the prospect of supporting their sons and daughters to manage a budget, possibly to employ staff, to keep financial accounts and to ensure that the services purchased are of an acceptable quality. There is clear evidence that the project has supported older carers to build the confidence to opt for individual budgets, and to manage them.

Evaluation Methodology

This evaluation drew on the following sources of information:

- ✚ Observation of the Oxford and Witney Carer Group meetings in May 2015.
- ✚ Focus group interviews with members of the Oxford, Witney and Wantage groups (10, 12 and 8 people respectively)²
- ✚ Telephone interviews with members of the Banbury group (n=2)
- ✚ Email questionnaire response from one member of the Oxford group³
- ✚ Email questionnaire or telephone interviews with professionals who have knowledge of the project⁴ (n=4)
- ✚ Telephone interview with the Chair of South East Oxfordshire Mencap, himself an older carer
- ✚ Observation at a Carers' Well Being event in Oxford in June 2015 attended by 11 local carers of adults with learning disabilities
- ✚ Interview with the Project worker.

In total, 34 (33%) of approximately 100 carers who have accessed the project to date contributed to this evaluation, and four professionals.

Results

The results are reported under the project outcomes:

- ✚ The project will reach a minimum of 40 older carers in its first year, and between 100 and 150 by the end of 3 years
- ✚ Older carers will have the confidence to start local informal groups
- ✚ Older carers will influence the strategic thinking of the local authority and clinical commissioning groups on need for planning to support older carers, and to make provision locally for their sons and daughters when they can no longer care
- ✚ Older carers will be better informed about their entitlements, those of their sons and daughters, and will know how to access local sources of support, information and advice
- ✚ Older carers will develop supportive relationships with others in their situation

² See Appendix 1

³ See Appendix 2

⁴ See Appendix 3

The project will reach a minimum of 40 older carers in its first year, and between 100 and 150 by the end of 3 years

This aim has been achieved. Between 30 and 40 people regularly attend monthly Carer groups in Witney, Wantage, Oxford and Banbury. Others do not attend groups, but have been in touch with the project worker individually. I noted in the mid term Evaluation that the project has extended beyond over 60s to embrace siblings and other younger relatives. This trend has continued.

Estimating precisely how many carers have been in touch with the project is difficult. Carers have many different ways to connect, and some prefer one to one email or telephone contact to attendance at groups. Furthermore, Changing Scenes has been a catalyst for other carer related developments, including

- ✚ the Health Watch commissioned Report 2014 to which more than 20 local carers contributed. Older carers remain actively engaged with the work of supporting people with LD/mental health needs and challenging behaviours and are contributing to a focus group that will draw on their experiences to identify what a peer support services should offer
- ✚ a Creating Family Champions course, funded by European Social Fund, and attended by 13 carers in January- End of March 2015. This is an OCN accredited course and was assessed at a level 3 accreditation, equivalent to A level standard.
- ✚ a Safe Places initiative, which has had concrete outcomes in Wantage, Didcot , Kidlington and Bicester⁵; and has been written into the OCC LD Big Plan indicating how carers are influencing local policy.
- ✚ a Well Being event sponsored by Age UK for National Carers Week in June 2015.



The numbers of carers in touch with the project has been augmented by referrals and recommendations from other agencies (for example Age UK), from professionals and by carers recommending it to others in their situation.

The funding for Changing Scenes has enabled other funding sources to be accessed to support family carers and strengthen their voice, in response to findings from the Project.

- OxFSN has been funded by OCC to train and support Quality Checkers, family carers who will be paired with trained members of local Self Advocacy group My Life My Choice to inspect local services as 'Experts by Experience'.
- ESF funding has enabled a Creating Family Champions course to be run.

⁵ Safe Places is a national scheme to set up safe places in shops, cafes, restaurants and public buildings where people can go if they are lost, feel threatened etc.

- HealthWatch Oxfordshire funded OxFSN to undertake a review of the needs of local families with sons and daughters with autism / mental health problems and challenging behaviour on the strength of its connections with local carers

Lessons for the future.

- ✚ It takes time to build momentum in projects such as this. A strong foundation has been built, and it is likely that were the project to continue, the numbers and localities reached would grow, aided by the multiplier effect of additional funding sources.
 - ✚ One size does not fit all. Carers have chosen to relate to the project in a variety of ways, not only through attendance at groups.
-

Older carers will have the confidence to start local groups

This aim has not been met. Every older carer interviewed has been adamant that they do not have the energy, knowledge or skills to manage and lead a group. It is not, in most cases, lack of confidence, rather lack of energy.

However, during the course of the project steps have been taken to address this.

Younger relatives, usually siblings, have been recruited to the project and are being supported by the project worker to attend groups and learn facilitation skills.

A Creating Family Champions course funded by ESF was run for 13 family carers in January- March 2015 . Funding for a further course for another cohort of carers is being sought.

Lesson for the future

This aim was unrealistic. Most older carers have spent a lifetime caring and fighting for resources to support their relatives, and are unlikely to be in a position to take on extra responsibilities. This is an argument for extending the age range, to include younger relatives and carers in their 50s.

Older carers will influence the strategic thinking of the local authority and clinical commissioning groups on need for planning to support older carers, and to make provision locally for their sons and daughters when they can no longer care

This aim has made significant progress since the initial evaluation. Then I reported carer fatigue. Now there is a considerable appetite to influence local policy and practice, and there are some indications that commissioners are more willing to listen.

Examples include

- The HealthWatch Report A Local Experience of National Concern (2014) which has influenced not only locally but also NHS England South. The report was passed via Oxfordshire Health Watch to Health Watch England who raised the issues in the report with the appropriate ministers, and responsible personnel at the Department of Health. The National Family Carer Network was invited to meet with the DH to discuss the issues it raised. As a result of the Report OxFSN was invited by DH to submit a bid for peer support to families who have relatives with learning disabilities ,mental health needs or behaviours that challenge. OxFSN are in a consortium with Royal Mencap Society, NDTi, Challenging Behaviour Foundation and Respond. If successful, Oxfordshire will be a pilot site for peer support for these families.

- Meeting of 20 carers with Bill Mumford, then head of Winterbourne Improvement Programme, in January 2014 to discuss the needs of carers of people with mental health problems,, autism and challenging behaviour
- Support for 5 older families who have relatives with learning disabilities and mental health needs/challenging behaviours and autism. Two families are supported at Care Programme Approach meetings by a Changing Scenes legal volunteer. These families feel isolation even within their peer group, as they are experiencing more extreme challenge and have very few support options available to them.
- Setting up a home for the sons of four Wantage carers whose families wanted them to live together as they had known one another since childhood. Said one of the carers 'We had been trying for 10 years to get this. Jan led us through the process, she interprets the mindset'.
- Commissioning from OCC for training family carers to be Experts by Experience, and to inspect local services, working alongside a local self advocacy group.
- Presenting carer stories at International Conferences at the Open University in 2013 and 2015, bringing the project to a wider audience, and supporting carers to build skills in speaking in public. 9 carers have been involved.⁶

A professional commented:

Older carers that we work with are vulnerable themselves and less inclined to question/challenge LA decisions. Many have no idea that they can indeed appeal decisions about funding/respite etc . Jan has completed essential work in motivating and encouraging carers to meet locally and talk about their concerns/hopes and needs. It would be a real shame not to continue this very essential piece of work. Strategically, Jan has supported many carers to attend countywide events to ensure that key stakeholders are involved and more in control of County decisions. The Big Plan meetings were strategic commissioning led and several carers across the whole of Oxfordshire attended and felt they were contributing to shaping the Plan as a whole

Case Study Fairer Charging

Fairer Charging is an initiative by OCC to review how much families should contribute to the cost of services used by their relative. It was under way at the time of this evaluation and affecting several people attending Groups. The Project Worker used the meetings to record how Fairer Charging was impacting on individual families. She will use these examples to challenge the Council to be more transparent in their justification for the decisions they are making. And to argue that certain decisions, over which Local Authorities have discretion, should be reviewed, such as a failure to disregard the impact of additional disability related costs on a family's income.

This process of influencing local decisions is in its early stages. A senior professional commented on its value:

This must be an independent role as the Local Authority have a conflict of interest in delivering support to carers. There is a niche role for the network to challenge the LA on its decisions, this will not happen effectively without the project being funded further

Lessons for the Future

⁶ An academic paper is in development as a result of these presentations

An explicit aim for such projects could be to act as a bridge and connector between local professionals and older carers.

Projects such as this are a vehicle for capturing the impact of austerity driven changes in local authority provision on older carers, and seeking to mitigate adverse effects

Older carers will be better informed about their entitlements, those of their sons and daughters, and will know how to access local sources of support, information and advice

This aim has been fully met.

Every carer interviewed emphasised the value of having a source not only of information, but of how to use it effectively. Furthermore, the value of the project to professionals was emphasised.

This is best illustrated by examples.

Case Study 'Belinda'

Belinda is 89. She lives in a small isolated village. Around 10 years earlier she had moved out of her home to enable her severely disabled daughter to live there with carers. Since then she has struggled to get consistent high quality care for her daughter. She said 'in 9-10 years, I've had nothing but trouble with carers. I've had to step in to do things they don't do, like keeping her finger nails cut. I've had to do shifts because they can't cover weekends or Bank Holidays'. She had been supported by the project worker to obtain legal advice, and ultimately change care agencies. However, the new provider was based almost 200 miles distant, and carers were not reliable. Furthermore, there was an ever changing population, distressing to a woman who dislikes change. The project worker, and her legal assistant were assisting her to move to Direct Payments which she would manage herself, and to employ local women whom she knows well as her daughter's carers. Other members of the group supported her, by relating how their lives had improved after moving to take control of the budget through Direct Payments.

I worked with an older carer who felt a worry leaving her daughter alone in the house when she had to go out. We put in a telephone with pictures so that she can direct dial her sister if she is worried, or if mum gets delayed. It has been reassuring. In future, she will be able to take the initiative to contact her sister for a chat or to arrange to visit.

(Community Occupational Therapist)

After the OT came to our group, he arranged an alarm system by the front door to deter unwanted callers if my boys are here alone.

After Danny went missing we got a tracking device on his phone, thanks to the OT who came to talk to us about what he can offer.

Our support in future depends on getting the assessment right. But I don't have a clue about what to say and it is on line, and I have macular degeneration and can't use the computer. Without the project I wouldn't have a clue. I dread PIP.

My wife was ill. I rang Jan. She got us a carer straight away

Until I came here, I didn't know what I didn't know

It's the only port in the storm of change around us

We have a really long wait for an assessment. Where else would we go to get our questions answered?

After attending the Family Champions Course I have begun to make a will to make sure my son is well provided for.

An unanticipated benefit of the project has been that it provides a bridge between professional whose job it is to support carers, and the people who need support. Said one professional:

Family carers do not know where to go for help. For someone in my position it can be hard to find them. Attending the groups has been an eye opener for me as someone whose job is outreach. It is so useful.

Lesson for the future

At times of considerable change, carers are vulnerable, and statutory authorities have conflicting interests, given their need to save money. An independent advisor and advocate is particularly valuable.

Older carers will develop supportive relationships with others in their situation

This project aim has been well met throughout. The bonds between members of the well established groups were palpable – the example of the four carers banding together to develop supported living for their sons is a good illustration of the practical benefits of such relationships.

The people who had recently joined the project were effusive about this aspect:

This is my first visit. It is excellent. You see the GP, or read about things on line, but you don't want to take up their time, you don't relax. Here it is open, you can say things that are on your mind.

I'm here to meet other people in a similar situation. It is a lonely business being a carer. Here I have friends can get support from knowing with other people are doing, just knowing I am not alone.

Meetings are lovely, stimulating

For a small minority it is the information rather than the mutual support element that is critical. There may be a gender element to this, as most attendees are women. A male carer from an ethnic minority emphasized the importance of information rather than relationships, and alone amongst the respondents would be prepared for an online forum, nevertheless he expressed preference for face to face meetings.

One of the groups is small, averaging an attendance of 3 people. A carer who attended this group commented:

It would be more valuable if more people came.

Lessons for the future

Groups and social contact are highly valued by many older carers

Groups are more effective if they have more than 3 regular attenders

Digital contact is not an acceptable alternative to face to face meetings for most carers

Anticipated Project Learning

Here I comment on the Anticipated Project Learning, drawing on evidence from the evaluation.

The best model for working in a rural county to deliver support to older family carers

This project has entailed funding an independent project worker who herself has a disabled son to work with older carers of people with learning disabilities and support them to access information and advice, in particular through setting up carer groups. It appears to be a very appropriate model for supporting family carers in a rural county. The project worker bridges the gap between carers and statutory services and commissioners, to the advantage of both sides.

The success appears to be attributable to several factors, most of which I identified in the Mid Term Evaluation (2014):

- ✚ The project worker is independent, hence is able to overcome the mistrust many carers have of the SSD, because of reputation, previous experience or lack of confidence.
- ✚ The project has been at a time when there is massive change, both at national and local level. This has made carers' needs for information and support more acute than it might otherwise have been.
- ✚ The project worker is herself parent to a disabled son, and is seen to understand the issues the older carers face. This helps trust to build.
- ✚ The project worker is well connected locally, has over time developed positive relationships with health and social care professionals, this means they trust her and know how she may be able to help people they are in touch with. This also helps when she is advocating for individuals.
- ✚ The project worker represents an organisation, Oxfordshire Family Support Network, which is highly regarded and well connected.
- ✚ The project worker has scope to define how she uses her time, is able to be flexible and respond according to need
- ✚ The project worker has undoubted skills in building and maintaining relationships, and is extremely well informed about carer entitlements

Lessons for the future:

Much hinges on the quality of the person in the project worker role.

Carers choose to relate to the project in a range of ways, not only through local groups.

In a rural area where no register of older carers exists it takes considerable time for a project such as this to become known to potential beneficiaries.

A model of planning and support that is holistic for the family and which enables health and social care to work in an integrated way

The model developed through Changing Scenes is undoubtedly one which is appropriate for a rural county. As one knowledgeable interviewee commented, many carers do not know where the boundary lies between welfare benefits and local authority services. The project is able to advise and support carers both on how to get the best out of Local Authority funded services, and how to interface with the Benefits system.

It was probably ambitious to expect it to enable health and social care to work together effectively, and given developments described above during the course of the project, this has not been

achieved. But the disadvantages have been mitigated for those carers in touch with the project thanks to the advice, advocacy and support available through the project.

How resources and information can be delivered in a way that reaches the target audience most effectively, as many are not able to utilise digital technology. This may involve partnership working with other organisations delivering training on the use of technology

Reading is not the same as hearing (older carer)

It is my firm conclusion that although a number of the carers engaged with the project use IT, this is not a replacement for personalized support. Whether or not this is a generational issue is not possible to say with any confidence. Even the most digitally savvy carers interviewed emphasise the value of meeting others, exchanging information, offering and receiving human support. A significant percentage of the carers contacted (21%), do not use IT for a range of reasons, and look to the project for support with on-line form filling.

The most effective way to mentor and support older carers to run peer to peer support groups

No, I would not run a group. I've done it before and my health and energy levels now don't permit me to take on extra things

Older carers are resistant to running groups. Some have done it in the past, but are adamant that self help does not work for people like themselves because of the time and energy required. However, through involving siblings, the Project worker appears to have found a way through this particular barrier. One sibling is co-facilitating the Oxford Group currently.

The externally funded Creating Family Champions course run by OxFSN is another route to recruitment of carers (most of whom are under 60) to run support groups, and act as advocates. A second course is being planned. This is likely to be a significant contribution to sustainability.

Lessons for the future:

Older carers are unlikely to be willing to take on the coordination of local groups

Extending the age range of potential beneficiaries may be a way of finding volunteer group coordinators

Focussed training, shadowing and mentoring are needed if unpaid coordinators are to be a viable alternative to paid project work

Understanding the barriers to carers making plans for the future and building effective support around them

I'm trying to plan ahead. But it is easier to just jog along

I reported on the barriers in my mid term evaluation. They were:

Barrier	Emerging solution
Painful to think about	Mutual support, encouragement to name the fear, and share it, means people are at the very least talking publicly about this
Lack of information about what is possible	Carers' groups as in this project
Mistrust of quality of services in the absence of a watchful eye	Circles of support, advocacy, engagement of siblings, involvement of carers in inspections as Experts by Experience
Ideas but do not know how to progress them	Independent advocate, well connected with services, who can provide information and act as

a bridge with service providers and commissioners

These still apply. In addition, this evaluation identified further barriers.

Barrier	Emerging solution
Need for legal advice	Recruitment of a volunteer who is an expert in community care legislation, to work with individual families
Professional relationships with carers are not sustained due to loss of expertise in statutory services, in particular specialist care managers and Disability teams, as Local Authority moves to mainstreaming solutions	Independent project worker who can navigate the corridors of power alongside or on behalf of carers
The Local Authority's need to make savings may create a conflict of interest in informing carers of their entitlements.	Independent and well informed project worker to ensure carers know what they should be able to expect.

Conclusion

The Project has significant achievements to its name. It has been hard to find anyone who has anything other than the highest praise for the work carried out under its auspices. Comic Relief can be assured that its money has been well spent.

- ✚ The project has reached over 100 people, in part through local groups but also through one to one contact, research projects and courses.
- ✚ It has enabled the budget holders to leverage funding and support from other sources to extend the influence and capabilities of local carers
- ✚ It has earned carers a place in discussions about strategic direction for local services
- ✚ Individual carers have made progress in planning for the future, and some have secured independent homes of choice for their relatives
- ✚ It has extended influence through research and conference presentations
- ✚ Steps are being taken to record the impact of Local Authority policy on older carers, with a view to campaigning for adjustments
- ✚ Plans are developing to sustain the project through self help, in particular through training Family Champions, and working alongside younger relatives
- ✚ There is a successful and replicable model of ways to support older carers
- ✚ It has developed a viable model of support for older carers in a rural area.

It has taken the full three years to build momentum in some parts of the county, and there remain challenges:

- ✚ To establish groups in other significant Oxfordshire towns, in particular Bicester, Abingdon and Didcot
- ✚ To support carers at a time of significant changes to Welfare Benefits, and in Local Authority provision for people with learning disabilities
- ✚ To develop volunteers who can take on some aspects of the Project worker's role.

To reap maximum benefit from the investment to date, a further period of funding should be considered. The emphasis should be on:

- ✚ Sustainability: to continue to develop volunteers who can undertake some of the tasks performed by the Project Worker, in particular facilitating local groups
- ✚ Campaigning: to capture the impact of changes on older carers, and to use the evidence to influence local policy.
- ✚ Document need: build a register of older carers so that the Local Authority understands the extent of their needs, and can plan accordingly
- ✚ Widening the scope: to extend the age range to carers over 50, and to younger relatives who may well become carers in time
- ✚ Acting as a bridge: to make the task of bridging the communication divide between professional and older carers an explicit aim.

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Jan Walmsley is an independent health and social care researcher. She holds Visiting Chairs at the Open University and London South Bank University. She is the author of numerous publications and reports in the field of learning disabilities, and in 1994 founded the Social History of Learning Disability Research Group. She has been a visiting scholar in Ireland, Australia and New Zealand, and was co-editor of the British Journal of Learning Disabilities 1999-2004.