



University of Brighton

Evaluation of the East Sussex Carers' Breaks Demonstrator Site

This is a summary report of the independent local evaluation of the East Sussex Carers' Breaks Demonstrator Site. The demonstrator site was commissioned and funded by the Department of Health as part of the 2008 National Carers' Strategy. The evaluation was undertaken by SSPARC at the University of Brighton and ran between October 2009 and March 2011.

Key Findings

- The respite breaks and other sources of support provided by the project have positively impacted the well-being of carers and often helped them to continue coping with their caring role.
- The project has provided mentally and physically stimulating activities for people with dementia, enabling social interaction and often improving the mood and well-being of service users.
- The project has often been successful in involving people with dementia who were reluctant to engage with services. This has been achieved through a person-centred approach through which relationships of trust with community support workers (CSWs) have developed.
- There were variations in the support provided to carers in terms of regular breaks and input from a CSW. In cases where more support was received this tended to have had a more significant impact.
- The project teams have established successful partnership working with the Older People's Community Mental Health Teams (OPCMHTs) in which they are based, and with other agencies. However, some problems with the efficiency of communication systems were identified.
- Challenges faced by the project have included finding ways to meet the growing demand for the service with limited staff resources, and managing transportation needs especially in rural areas.

Research Findings

March 2011

Background

The East Sussex Carers' Breaks Demonstrator Site was funded as part of the Department of Health Carers' Strategy. A national evaluation is currently taking place of demonstrator sites across the country with a final report due in September 2011 (CIRCLE, 2010).

East Sussex has the second highest proportion of people with dementia of any local authority in the country, affecting 10% of women and 6% of men over 65 (Alzheimer's Society, 2007). In recognition of the need within the county for support for carers of older people with dementia, pilot projects had previously been set up in Eastbourne and South Wealden. The aim of the East Sussex Carers' Demonstrator site was to expand these existing pilots across the county.

Service users are referred to the project through Older People's Community Mental Health Teams in five areas: Eastbourne, South Wealden, Hastings and Rother, Seaford and Ouse Valley and High Weald. The project offers short respite breaks to carers through simultaneously supporting people with dementia either through group activities or one to one support.

Research Methods

The main aim of the evaluation was to gain a greater understanding of the views and experiences of those using and involved in providing or referring to the service. It was felt that qualitative methods using interviews were most appropriate in order to gather in-depth information from participants. Data from these interviews were analysed thematically.

Interviews were conducted with 21 carers. Carers were interviewed twice in order to assess the impact of the project upon the carer and person they care for, over a period of time. Interviews were also conducted with community support workers (CSWs), the project manager, resource officers, care coordinators who had referred to the project, partners from voluntary and community organisations (VCOs) and one steering group member (who was also a carer who had received support from the project).

Evidence was also gathered through observation of groups, attendance at project meetings, and analysis of project data and feedback forms.

Support received

Amount and type of support

For recording purposes a 'break' constitutes 2.5 hours. However, the number of breaks received from the project by the carers interviewed, varied from less than one break per week to more than five. Some carers were also receiving other support e.g. through traditional day care services.

In most cases those being cared for were participating in a project run group (based either in a day care or community centre and/or an 'Out and About' group). Some groups were 2-3 hours, whilst others covered most of the day. The provision of the latter increased over the course of the project, thus offering longer breaks to the carers of those attending.

Three carers were supported to attend a mainstream community group but in one of these cases this was on hold by the second interview. At the time of the first interview, eight service users were receiving one-to-one support, but this number was reduced to three by the second interview.

How carers use the breaks

The short respite breaks enabled carers to do a range of activities during their breaks, including social activities and relaxation. However carers were most likely to use their breaks to carry out practical tasks at home or shopping. Carers found this valuable since it was often difficult for carers to go out or even to do housework whilst caring for their relative.

Not all the carers received a physical break. Some carers were at work during the 'break'. Some were non-resident carers, caring for a parent. In those cases, carers experienced this as a 'break from worrying'. Others received a break from phone contact enabling them to concentrate on tasks which may otherwise be difficult to carry out. Two non-resident carers, however, felt the impact of the project on themselves was minimal.

Some resident carers and those they care for were anxious about being separated. Although initial reluctance was often overcome as service users built a relationship of trust with the CSW, others continued to need the support of their carer. Therefore some couples continued to participate together. Although this did not give the carer a physical break, it provided a break from the usual routine, and carers valued the input from a support worker. Where couples took part together in group activities this also provided carers with an opportunity to make new friends and increase their social support network.

Emotional and practical support

Alongside the benefits received through short respite breaks, many carers valued the emotional and practical support from their community support worker. Some spoke of the reassurance of knowing that the CSW was 'at the end of the phone'. In addition some carers benefited from involvement in carers' support groups but the amount of extra support received varied. Some carers were actively involved in the project and had developed a close relationship with their CSW. However, a few carers reported to have had little or no contact with a CSW following the initial introduction, and had no contact with other carers.

Health benefits

Most carers felt that the project had been beneficial to their health and well-being through relieving stress and anxiety associated with the caring role. In addition, at least one carer was also enabled to attend medical appointments. However, the extent of the support received is likely to be an important factor in affecting both mental and physical health.

The condition of people with dementia often worsened during the course of the evaluation. Nevertheless, service users were in most cases reported to enjoy their participation in the project. Involvement was perceived to have a positive effect on mood through providing a sense of purpose and motivation. Activities providing mental stimulation were also felt to have a positive impact upon service users, possibly modifying the deterioration caused by the dementia in some cases.

What works?

The key factors identified in the success of the model were:

- Building a relationship of trust between skilled support workers, carers and service users.
- Working in an integrated way with the carer and person with dementia.
- A person-centred approach, focussing on the person and not the condition.
- Providing opportunities for social interaction and mental stimulation.
- Involving carers and people with dementia in the development of project activities.
- Being linked in with other statutory, voluntary and community services.

Challenges

Staffing issues

A key challenge was to meet the growing demand for the service whilst maintaining quality and flexibility. The support received by some carers was felt to be insufficient and inconsistent. Because of the demands on the service, the project employed a strategy of training other agency workers to provide support to service users and handing over where possible. However, where this had been put in place, service users were dissatisfied with the new service and subsequently withdrew. Staff and partners also noted challenges experienced with using agency workers in group activities. One care coordinator felt that the strategy of recruiting and training agency workers was a risky investment and that more fully trained and experienced staff were required.

The project aims to withdraw its support of service users being accompanied by a CSW to attend

mainstream community groups, once establishing the confidence of community workers. However community partners felt that this would not normally be possible since they did not have the resources or skills to include those with high support needs without the aid of a CSW. This raises some questions about the sustainability of this approach.

Transport

Transport was a problem in all areas but particularly in High Weald due to its more rural character. Where carers were not able to transport their relative to a group, CSWs would often provide transport but they were not always able to do so. NHS voluntary transport services were sometimes referred to but not always available. Trained staff were required to collect service users who could often be nervous or confused about going to a group.

Communication

Communication between CSWs and care coordinators usually took place on an informal face to face basis, but where staff were not based in the same building this could be problematic. Staff also identified problems caused by having to record notes on two systems. Some care coordinators identified a need for more regular reports and contact with CSWs.

Owing to the demands on the time of project staff, some carers were less informed than others about the project and about other services and opportunities that may be available to them. One CSW felt that it would be useful to produce a leaflet to provide to carers on or before their first visit to explain the purpose of the project, the types of breaks that could be offered and other sources of support available.

The implementation of regular reviews involving carers, service users, CSWs and care coordinators would be helpful in many cases where this was not currently being put into place.

Conclusion

The project has been hugely beneficial to many carers through increasing well-being and helping them to cope with their caring role. People with dementia have also benefited from their involvement. The success of the project, however, is dependent upon provision of sufficient skilled staff in order to maintain the flexibility and person-centred character of the service, whilst at the same time increasing the amount of hours and number of people accessing support. Organisational issues around transport and communication also need to be addressed in order to increase efficiency and continue to provide the high quality and greatly needed support delivered by the project.

Learning points

- A key success factor of the project is the relationship of trust built between the CSW and the carer. But such relationships did not always develop. Some carers did not have regular contact with a CSW because, for example, the carer is working or because the CSW does not provide transportation to the person with dementia (and therefore does not visit the carer's home). It is therefore important for the project to identify those for whom this is the case and where the carer may be socially isolated. In these cases it would be useful for the project teams to explore means of ensuring that these carers are kept informed and in contact with a support worker. Written information may be useful as well as telephone contact and scheduling face to face meetings and reviews with the carer.
- The amount of support received by carers and service users varied significantly and there did not appear to be a clear correlation between need and amount of support received. This was rather dependant upon capacity of individual CSWs and availability of appropriate group activities. Data recorded on the project database as to the number and type of breaks received per carer was largely incomplete. It would be useful for CSWs to systematically record the number of breaks received per carer per week/month. This would enable resource officers to have an overview of resource allocation and more easily identify those who may be in need of further support.
- In addition to the degree of contact, the skills and experience of the support workers is also a vital factor in the success of the model. Recruitment of and referrals to agency workers provide a solution to meeting the increasing demands on the service. However often agency workers are less appropriately skilled or qualified for this type of work. This therefore needs to be handled carefully. Where cases are handed over to sitting services, it may be useful for the CSW to remain in contact for a period of time in order to respond to, and report back any difficulties experienced by the service user or agency worker.
- Sufficient staffing is vital for the quality and flexibility of the service to be maintained, whilst increasing the number of people able to receive support. Extra funding is therefore necessary. If this is not available, the project should explore introducing a charge for the services provided. Where this was discussed in interviews, most carers indicated that they would be willing to make a financial contribution. However this would only be appropriate after a trial period, through which carers and service users could build a relationship with a CSW and be made aware of the benefits of the project.
- The success of the project is also dependent on effective links with other services. Although the project has generally worked well with partners, some communication issues were identified. In particular, it is important where CSWs do not normally see care coordinators on a regular basis, for project teams to consider how channels of communication could be improved or existing systems clarified and reinforced. When care plans are created, it may be useful for CSWs and care coordinators to schedule regular telephone or face to face meetings to discuss how cases are progressing.

References

Alzheimer's Society (2007). "Dementia UK statistics" from: http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=4

CIRCLE (2010) National Carers Strategy Demonstrator Sites National Evaluation: Interim Report. Centre for International Research on Care, Labour and Equalities, University of Leeds

Further information

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The full report of the East Sussex Carers' Breaks Demonstrator Site evaluation is available on the University of Brighton, Social Science Policy and Research Centre publications web page:
<http://www.brighton.ac.uk/sass/research/publications/>

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