

Day care in rural areas

An evaluation of four small innovative day centres established by Age Concern Northern Ireland between 1991 and 1994 in rural areas showed that day care offers one means of meeting the needs of older people with dementia for social and intellectual stimulation and their carers' need for respite. However, the location made particular demands upon the service. Faith Gibson, Dorothy Whittington and colleagues from the University of Ulster who carried out the study found that:

- f** Short-term project funding may have created pressures to translate an urban model into a rural context with insufficient attention to differences in geography, demography and attitudes towards using care outside the home.
- f** The rural location exacerbated well-known problems of uptake, access and regular attendance. The geographical distribution of the users and other resource constraints curtailed the hours of care provided.
- f** Shared premises kept the costs down but meant a lack of secure storage for records, equipment and materials; these had to be transported daily between centres in staff members' cars, with numerous attendant hazards.
- f** Having more than one salaried member of staff was crucial to ensuring reliability, stability, continuity and quality of service. Management, supervision, training and support were critical to the centres' success but were complicated by distance.
- f** Volunteers working alongside salaried staff provided reliable complementary assistance. They were absolutely central to the centres but did not always appreciate how pivotal their contribution was.
- f** Most carers had previously received no services. They perceived the centres as providing respite for themselves, for which they were immensely grateful, and a change of scene for the users. Carers showed little interest in or knowledge of what happened in the centres. They were confident people were being well looked after and that "most enjoyed having a day out", benefited from a "change of scene" and "meeting other people".

Background

Building on its Belfast-based experience, Age Concern Northern Ireland's three-year Rural Action on Dementia Project, funded by charitable trusts, established four small day centres for people with dementia living in rural parts of counties Tyrone and Fermanagh. Peripatetic Age Concern staff and local volunteers used premises owned by other organisations to provide day care designed to give social stimulation to users and provide respite for carers.

The establishment of the project preceded the introduction of formal contracting by statutory purchasers but by the end of the project the two centres in Tyrone were awarded a formal rolling contract between Age Concern and the Western Health and Social Services Board (the integrated statutory health and social services authority). This enabled these centres to continue and others to be established in additional villages. In Fermanagh no contract was secured and the centres there were taken over by the Board.

Capital costs were minimal for Age Concern as the centres used premises owned by others. Salaries, travel and vehicle costs, administration and volunteers' expenses accounted for 95 per cent of revenue costs.

The centres

Accommodation owned by the Western Health and Social Services Board, community groups and churches was used. Each centre opened one day weekly except one in Fermanagh where two groups living in different geographic locations attended on different days. Centres were staffed by a peripatetic co-ordinator, minibas driver/carer and latterly by an additional care worker, augmented by regular local volunteers.

Forty-seven users, 17 men and 30 women, aged 66 to 91 attended the centres during the three-year period. The average age for men was 77 and for women, 80. The people attending the centres were a very frail group, with 16 (34 per cent) dying and a further 7 (14 per cent) moving into permanent residential or nursing home care by the end of the study period.

People were referred by social workers, community nurses and a small number by neighbours. Joint initial assessment visits by the referring professional and the project co-ordinator were undertaken.

Attendance

Each centre differed in start-up date, size, ethos and attendance. The smallest centre had four attenders

and the largest never more than nine. Reasons for variable attendance included ill health (including temporary hospitalisation), respite care admissions, inclement weather, reluctance to attend, the carer's inability to facilitate attendance, leaving the locality and permanent admission to hospital, residential or nursing home care.

It took longer than anticipated to establish the centres, to obtain referrals and to achieve viable numbers of people with mild to moderate dementia who were sufficiently physically fit and mobile to be able to attend.

Transport was provided by a minibas equipped with wheelchair ramp owned by the project whose driver/carers held one-year job creation appointments sponsored by the government. All the well-known problems associated with day centre transport which make for a very short care day were exacerbated by distance, a scattered population, weather, poor roads and other local conditions.

Relationships between Age Concern and the statutory authority

Rent-free accommodation for two locations and a capital improvement grant for another, meals purchased from hospitals and a subsidy to some volunteers' expenses helped reduce capital and revenue costs incurred by Age Concern.

Relationships with key health and social services professionals consisted of regular formal meetings of senior managers, an interprofessional steering group of directly involved professionals (soon abandoned), and informal contacts related to individual users. Relationships flourished in one county and became exceedingly strained in the other. Differences in expectations and beliefs about social welfare, perceived care practices and professional perspectives as well as anxiety and competitiveness in a period of transition to the 'mixed economy of welfare' emerged as possible explanations for these very different outcomes.

Staff and volunteers

The project weathered a succession of crises due to staff sickness, accident and prolonged absence. Training and supervision were complicated by arm's-length management from Belfast which placed excessive demands on individuals in times of crisis. The service was sustained because of the remarkable commitment of a small number of people, including volunteers.

Eighteen volunteers, whose ages ranged from 20 to 73, provided outstanding service sharing all but record-keeping and management tasks with paid staff. Volunteers were mostly recruited by personal

contact by Age Concern and Social Services staff. In one centre the local branch of Age Concern provided volunteers on a rota basis. All others attended regularly each week and in Fermanagh some frequently attended two or three days weekly. Although crucial to the operation of the centres, they did not see themselves as making a particularly central or pivotal contribution. Given more systematic training and regular support it is likely that volunteers may have been able to make an even richer contribution because of their local knowledge and their acceptability to carers.

Day care programme

Centres provided an enjoyable day out in a warm, informal, relaxed environment in which general social and recreational activities, some personal care and a warm meal were provided. Health and safety regulations were cited as the reason for users not participating in domestic tasks. More attention to the specific assessment of present capabilities and to using the fine-grained detail of each person's unique life history, including their rural past, could have enriched the programme for individuals and small groups.

The accommodation placed some constraints upon the programme and restricted activities. No centre had adequate, secure on-site storage. Peripatetic staff and the crises which beset them meant that sometimes materials were not readily available. Secure storage would also have promoted more systematic, comprehensive record-keeping.

The carers

Before the project, few carers had received any services. They found it difficult to identify the impact of the centres on the users and had little direct knowledge of or interest in knowing what actually happened in them. They appreciated contact with the staff and volunteers who travelled on the minibus. They unreservedly trusted the staff and volunteers to care for their relatives and were unanimous in their conviction that the centres sustained them in their caring responsibilities; all wished the centres to continue under Age Concern auspices. Their high levels of satisfaction and their low level of demand are typical of new service users in rural areas who have been unaccustomed to articulating needs or demanding assistance.

Conclusions

Urban models of care do not necessarily translate well to rural communities. Careful analysis of the demographic, geographic and administrative contexts and much detailed planning is required to

achieve successful rural service innovation. Differences in ideologies of welfare and competitiveness both within and between organisations may jeopardise innovation.

Short-term project funding and time-limited service contracts may be seductive and put undue pressure on independent sector service innovators to take short cuts and underestimate costs. In the end, this may be detrimental to achieving stable, well-used, durable, high quality provision.

The complex, multiple and changing needs of people with dementia and their carers are unlikely to be met by a single service response. Careful assessment of local conditions, existing services and the needs of individuals are all important. Highly individualised care is required. Dementia specific day care may not be appropriate for all contexts and will certainly not meet the needs of all older people with dementia who live in rural areas. Some communities may be better served by local, readily accessible, small-scale, generic day centres rather than by provision tailored specifically towards people with dementia.

Such centres would need to be sufficiently well-staffed and flexibly managed to provide individualised and small group care within a more general ethos. Core salaried staff could be usefully complemented with well-trained and well-supported volunteers. Sometimes day fostering of either individuals or very small groups or mobile centres might provide a more responsive, accessible and cost-effective service.

There is no one best model. Day care, in whatever form, should only be one part of a comprehensive dementia service which is always likely to cost more and be more difficult to provide in rural areas. Purchasers and providers need to be willing to seek and to heed the views of users and carers, notwithstanding the reluctance of some consumers to express negative views for fear of being deprived of services. The Age Concern project found that using formal and informal channels of communication was crucial to building and maintaining effective relationships with users, carers and other key health and social services agencies.

Any comprehensive service needs to include arrangements to ensure early diagnosis, assessment and treatment; information; financial help; advice, counselling and support for carers and people with dementia; various domiciliary services; regular, casual and emergency respite care; and, when appropriate, permanent care in small, local, congenial, well-designed facilities. Because people living in rural areas are less well provided for, there needs to be continuing attention to their needs and

circumstances if innovative, creative and imaginative services are to be established and equity of service provision achieved.

About the study

Extensive periods of participant observation within the centres and examination of records, daily diaries and other documents were undertaken. Semi-structured taped interviews with 8 Age Concern staff, 26 carers, 16 volunteers, 5 senior health and social services managers and 11 direct service professionals and repeat interviews with some informants after some 12-18 months were undertaken. Andrew Pattenden, Lisa Rahmin and Deborah James were members of the research group.

Further information

Further information can be obtained from the authors at the University of Ulster, Shore Road, Newtownabbey, Northern Ireland BT37 ORL.

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