

Support Groups for Older Family Carers of People with Learning Disabilities

SUMMARY

The British Institute of Learning Disabilities (BILD) worked in collaboration with six local authorities in England to set up and evaluate local support groups for older family carers of people with learning disabilities. The groups proved to be effective ways of increasing carers' knowledge of services and giving them greater confidence in the future. The need for such work was demonstrated by the continuation of all but one of the groups. The groups also stimulated the local authorities to re-evaluate their relationships with and the support they provided for older family carers.

BACKGROUND

This project was one of several funded under the Growing Older with Learning Disabilities (GOLD) programme at the Foundation for People with Learning Disabilities. The British Institute for Learning Disabilities had previously made contact with a number of informal groups for family carers (Harris, 1998). The benefits reported by participants included:

- Emotional support from others who shared their concerns
- Practical suggestions and problem solving
- Exchanging information
- Gaining access to information about current service provision and future plans
- Influencing local policies and service developments.

It was believed that family support groups could also provide opportunities to:

- Address minor problems before they multiply
- Inform older family carers about current services
- Consult with family carers about proposed new developments
- Canvass the views of family carers.

BILD's proposal was to facilitate the development of and evaluate support groups targeted at older family carers in six diverse local authorities in England. Older family carers have been identified as being particularly disadvantaged in their knowledge of and access to services (Walker & Walker, 1998). This work fits well into the requirements of the recent White Paper in England which expects local authorities to prioritise work with family carers of people with learning disabilities over the age of 70 (Department of Health, 2001, Thompson, 2001).

THE RESEARCH

Local authorities were invited to participate in the project. They had to be willing to second a worker for 2-3 days a month to act as the local co-ordinator and to provide funding for any expenses involved in running the groups. The six authorities selected included rural and urban environments and had diverse ethnic populations.

The co-ordinators were all local authority employees: mainly social workers but they also included day and residential services' managers and a challenging needs specialist. Three authorities appointed more than one co-ordinator. In total seven groups were set up including two specifically targeted at male carers and carers from minority ethnic communities respectively. The groups met either weekly or monthly. Evaluation of the groups included verbal and written feedback from both the co-ordinators and participants.

THE FINDINGS

Co-ordinators needed to invest just over two days a month to support monthly meetings. This included time to arrange venues, transport and speaking directly with family carers to ensure their individual needs were met to enable them to attend. Where weekly meetings were arranged, five days a month were necessary.

Groups that managed the best were those that had two co-ordinators: to provide the necessary support, or just so that one could cover for the other if they were absent for any reason. Co-ordinators needed to be knowledgeable about learning disability issues and have some experience of running groups.

There were advantages and disadvantages for both participants and the co-ordinators themselves in being local authority employees. It was difficult for them to be independent. On the other hand they could facilitate access to services for participants.

Sufficient funds to cover expenses including room hire, materials, transport and refreshments were essential. Group members valued involvement in spending decisions.

Group members often felt more comfortable being defined by the age of the person they cared for rather than by their own ages. The groups variously sought 'older carers' or those who were supporting a relative over 40 years old.

Information leaflets about the group were useful but these needed to be followed up with personal contact. Time invested at this stage paid dividends as some family carers needed encouragement to attend. Adverts in local papers, libraries and other public places proved much less effective than directly targeting known older carers. After the groups began 'word of mouth' led to increased membership.

The groups, whilst mainly parents, also included siblings and 'foster' or adult placement providers. Some members were occasionally accompanied by the person with learning disability they cared for. This mixture did not present obstacles to the groups' functioning. That said the participants of the targeted groups for black and male carers were appreciative of their opportunity to meet separately. The wide differences in the needs of the people with learning disabilities they were supporting similarly did not stand in the way of the group's success.

The groups used a range of venues from 'neutral' hotel facilities to local authority offices. What was important was that the space was acceptable to the group members and constant as when venues changed the numbers attending dropped. Some participants particularly valued using council property as it signalled that the meetings were endorsed by the authority.

A weekly meeting schedule was very demanding for all involved and was only viable on a time-limited basis. Monthly dates were best set two or three meetings in advance in discussion with the participants. Some participants valued reminder calls prior to each meeting. The attendance of many members was dependant on reliable transport being arranged.

The best time during the day to fit in with caring responsibilities proved to be mid-morning lasting for two hours. Lunch afterwards was popular in allowing conversations to continue and enhancing the social element of the group.

Group size varied due to a variety of factors including weather, transport difficulties and health. In the main the participants valued smaller groups (less than 15 people) so they each had an opportunity to be involved in discussions. Active facilitation of the groups was welcomed to ensure people had fair chance to take part and to avoid individuals dominating.

An import aspect of the first meetings was for the carers to share their own experiences. The co-ordinators needed to be prepared to hear about very negative attitudes towards services which were common amongst group members.

The information provided needed to be relevant to the groups' needs and honest so that it did not raise unrealistic expectations. The participants themselves were a vital source of knowledge for the other group members, for example, giving advice on home adaptations. A newsletter or written summary of the information given at each meeting was appreciated.

The contents of the meetings covered benefits, current services, meeting age related needs, and planning for the future. The participants were also keen to explore how consultation with families could be improved.

Collectively the groups were able to draw attention to concerns and make complaints about local services which they may have felt too vulnerable to raise alone.

The potential social element of the groups could not be underestimated. Several of the carers were very isolated.

All but one of the groups wanted to continue meeting and all but the men's group are, which confirms the value of this type of family support. Some have sought additional funding and some have been taken over by local voluntary groups.

The participants particularly valued the opportunity to meet up with people in similar circumstances and their involvement led to practical outcomes including writing wills, increased benefits, accessing short-break services and paying additional attention to the health care needs of their relatives and themselves.

The groups also had a profound effect on the co-ordinators. One person said it had 'totally changed my view of family carers'. They were also regarded as a catalyst to changing relationships between families and services.

IMPLICATIONS

- Family support groups are proven to be a valuable and cost effective way of developing work with a range of older family carers across a variety of locations.
- The project showed that the skills to organise these groups are readily available within local services although co-ordinators can benefit from structured support to give them confidence to undertake their role (as was provided by BILD here).
- The potential for role conflict needs to be acknowledged where co-ordinators are employed by service providers.
- Groups are an effective starting point for achieving a broad agenda of work with older family carers, including finding carers, providing information and support and involvement in consultation and service development.

REFERENCES

Department of Health (2001). Valuing People: A new strategy for learning disability in the 21st Century. London: The Department of Health.

Harris, J. (1998). Working with Older Carers: Guidance for Service Providers in Learning Disability. Kidderminster: BILD.

Thompson, D. (2001). Valuing older people with learning disabilities in England. Update vol.2(18). London: The Mental Health Foundation.

Walker, C. & Walker, A. (1998). Uncertain Futures - People with learning disabilities and their ageing family carers. Brighton: Pavilion.

For Further information about the GOLD programme contact David Thompson, Project Manager, The Foundation for People with Learning Disabilities.

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The Mental Health Foundation
7th Floor, 83 Victoria Street, London SW1H 0HW
Tel: 020 7802 0300 Fax: 020 7802 0301

The Mental Health Foundation Scotland
5th Floor, Merchants House,
30 George Square, Glasgow G2 1EG
Tel: 0141 572 0125 Fax: 0141 572 0246

E-mail: mhf@mhf.org.uk
Website: www.mentalhealth.org.uk

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