

## **Good practice guidelines in supporting older family carers of people with learning disabilities**

### *Guideline 5: Involving older family carers*

*'We keep trying over and over again because we can't give up on our sons and daughters'* Older family carer, Sharing Caring Project, Sheffield.

The establishment of Learning Disability Partnership Boards as a direct outcome of *Valuing People* gives people with learning disabilities and family carers the opportunity to make a real contribution to the implementation of the White Paper.

The value and importance of involving both family carers and people with learning disabilities themselves in consultation and planning structures cannot be overestimated. Many of the most positive changes in services, support and opportunities for people with learning disabilities have been brought about through campaigning and lobbying by family carers themselves and, more recently, through the growth of self-advocacy organisations. Whilst family carers of any age bring a valuable perspective, older family carers have a particular wealth of practical experience to share. Most of the guidelines included here apply to effectively involving any family carer representatives, not just those who are older.

#### **ROLE OF FAMILY CARER REPRESENTATIVES**

Alongside other Partnership Board members, the role of family carer representatives is to help work towards implementing the vision in *Valuing People*. Their particular expertise is to look at how proposals may impact on families, and in looking at the long-term implications of decisions family carers have a unique perspective. In particular, this means they act as advocates for family carers – not only for those with relatives accessing services, but also those not currently accessing services for whatever reason. Involving family carers at this level also provides an essential invaluable mechanism for building stronger relationships between families and professionals.

## RECRUITMENT AND REPRESENTATION

The process of recruiting family carers representatives to Learning Disability Partnership Boards varies widely across the country. Some areas have held elections by contacting all family carers known through their databases or registers<sup>1</sup>. Others have invited family carers already active in local groups to join the Board or requested representation from local carer groups. Most family carer representatives are involved in some kind of family carers' network and do aim to ensure that the activities of the Partnership Board are known to other family carers.

It is the responsibility of the Partnership Board to help their family carer representatives to be as representative and involved as possible. They also need to be flexible about the number of family carer representatives involved rather than adhering to the fixed number of two as stated in the guidance accompanying *Valuing People*. Many family carers find it more effective to work on specific issues within sub groups of their Partnership Board. It is therefore important to recruit more representatives and ensure there are mechanisms in place to enable family carer representatives to feedback to each other and bring feedback to the wider Partnership Board meetings. It is the Partnership Board's responsibility to ensure the family carer representatives selected by whatever means are able to represent the views of a wide group of family carers. This shared responsibility is very important as there is a danger that one way to marginalise family carers views is to say that they are not representative. Examples of good practice undertaken by some Partnership Boards<sup>2</sup> include:

- regular open forums of family carers as a resource for wider consultation
- databases of family carers willing to comment on proposals, whether by phone, email or post
- opportunities for groups of family carers to meet and talk with Partnership Board members.

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<sup>1</sup> 'Good Practice Guideline 1: Identifying older families' produced by the Older Family Carers Initiative as part of this series highlights examples of databases used to ensure the two way flow of information between family carers and services.

<sup>2</sup> This information is informed by the comments of family carers representatives at regional family carer network meetings held in the West Midlands and Yorkshire & Humber, organised by the Valuing People Support Team

## ENCOURAGING OLDER FAMILY CARER REPRESENTATION

It is important to understand the context for involving older family carers in the consultation process. Not all older family carers wish to remain involved in decision-making processes other than those that directly impact on their situation. Some are restricted from being more involved by their caring responsibilities or by age-related barriers such as hearing and mobility difficulties. Others, who have been involved for many years, identify themselves as having ‘consultation fatigue’ – they have no more energy for this by having input on countless occasions without seeing any real change in their daily experiences. Others have chosen to ‘retire’ and focus on caring and coping on a daily basis. Despite this, a good number of older family carers remain involved and at the forefront of change because they want to do everything they can to ensure positive futures for the people they care for.

Statutory organisations need to be pro-active in building positive relationships with family carers and respect the lifetime experience of advocating and caring that most representatives will have. It is vital to have representation of both family carers where the person is no longer living with them and those where they are – otherwise there is a danger that the former will be discounted and the vital role they fulfil ignored.

Family carer representatives want to be involved as early in the process as possible to feel really involved rather than brought in to endorse decisions that have already been made. It is very important that representatives are given the information they need to understand the timescales for meeting deadlines, the context of different issues and the priorities driving the agenda of the Partnership Board and other consultation structures. There needs to be commitment on all sides to be open and transparent decision-making processes and services need to be held accountable to these processes.

## OVERCOMING PRACTICAL BARRIERS TO INVOLVEMENT

There are a number of practical barriers that particularly impact on older family carers, making it difficult for them to be involved in Partnership Boards and sub-groups. These barriers can be easily overcome through a commitment from the Partnership Board to making the meetings as accessible as possible for all representatives. For example, when planning meetings:

- always remember that spare time for family carers is very precious and should never be wasted.
- think about meeting times. Although it can be difficult to please everyone, many older carers prefer meetings during the day. Equally, meetings are difficult during school holidays as many take on responsibility for their grandchildren at this time.
- ensure that paid workers prioritise attending meetings or at least send a suitable replacement where there are family carer and service user representatives present so that representatives feel their presence and time is valued.
- be clear about the purpose of the meeting, the intended outcomes and what the process of their further involvement might mean so everyone has the same understanding.
- ensure that the practicalities of meetings are thought through. Where possible ask representatives what facilities and support they need. This may include ensuring there is good access by car or public transport and finding venues that cater for people with hearing impairments where microphones can be used or induction loops are available. Free transport should be offered to representatives, particularly those who might otherwise be unable to attend.
- be proactive in offering to reimburse family carers for any expenses they may have incurred to attend meetings and offering to pay them for giving up their own time to become involved in meetings.
- any paperwork for use with older family carers should be in at least a 14-point font size, and presentations need to be easy to read with copies available for those who prefer. Where possible, circulate meeting papers at least two weeks early to give representatives time to digest them, seek more information where necessary and gather feedback from other family carers.

## SUPPORT FOR FAMILY CARER REPRESENTATIVES

Being a carer is a full-time job and family carers need support to become representatives. Partnership Boards need to ensure that mechanisms are put in place to support their family carer representatives. In some areas this role is fulfilled by voluntary organisations working with family carers, in other areas statutory services have been providing this supporting role<sup>2</sup>, for example with a link worker.

Family carers volunteering to be representatives on both Partnership Boards and sub-groups should be given an induction pack with information to support them in their role. Information within the induction pack will vary by different area but should include the following basics and be updated regularly.

- Copy of *Valuing People* and other key paperwork such as Joint Investment Plans.
- List of Partnership Board members, their roles, responsibilities and contact details.
- Calendar of future meetings as well as key target deadlines for the Partnership Board.
- Clear statement of the aims and remit of the Partnership Board and how it links into other groups and processes.
- Guidelines on the role of family carer representatives.
- Expenses forms.
- Contact details, role and responsibility of a link worker to liaise between family carers and the Partnership Board.

The link worker should have responsibility for ensuring the continuing involvement of family carers in the Partnership Board and any sub-groups. A statutory worker or voluntary organisation could fulfill this link role but it is potentially a large job that would be difficult to fit into an already busy schedule. Funding needs to be identified to enable the link worker to provide the necessary support to representatives:

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<sup>2</sup> This information is informed by the comments of family carers representatives at regional family carer network meetings held in the West Midlands and Yorkshire & Humber, organised by the Valuing People Support Team

- taking an active role in helping prepare for meetings, perhaps through holding pre-meetings. This should ensure family carer representatives are clear on the procedure and the points they want to raise.
- with disseminating information to other family carers and gathering their views, maybe through planning and publicising meetings that enable family carer representatives to feedback.
- by organising meetings for family carer representatives to meet with each other, with other family carers and/or workers, and funding the costs of transport, breaks services, photocopying, refreshment, telephone, internet and postage.
- being supportive if family carers need to bring the people they care for with them to the meetings.
- providing a link between the chair of a Partnership Board or subgroup. This helps make these officers more approachable and accessible to the representatives and ensures that the officers are aware of the representatives' needs and can actively involve them in meetings.

## **DISSEMINATION AND FEEDBACK**

Continued involvement and support from family carers and their representatives is only assured if they know that they have been listened to. Therefore, Partnership Boards need to ensure that effective two-way communication mechanisms are established to disseminate information between representatives, their wider constituency and services. Involving family carer representatives in Partnership Boards does not absolve services of their responsibility to ensure that other family carers are informed of developments and the opportunity to have their say. Partnership Boards need to be creative in their approach to involvement, producing regular newsletters, organising local road shows and meetings as well as conducting telephone and postal surveys. Mechanisms also need to be developed to monitor and review the effectiveness of these consultation processes.

Older family carers have a wealth of experience to share with Learning Disability Partnership Boards and sub-groups. It is critical

that systems are established to develop constructive and positive relationships to drive forward the objectives of *Valuing People*. Older family carers, as with all family carers, are motivated by a desire to ensure that the right services and support are in place for those they care for so that they can continue to care and have confidence and peace of mind for the future. Success will be assured if everyone keeps in mind the common goals that unite family carers and services.

## REFERENCES, RESOURCES AND USEFUL CONTACTS

Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st century planning with people towards person centred approaches – guidance for partnership boards* London: Department of Health.

Department of Health (2001) *Family Matters: counting families in* London: Department of Health

### **[www.lifetimecaring.org.uk](http://www.lifetimecaring.org.uk)**

A website that focuses on raising awareness of the needs of older family carers and their adult relatives with learning disabilities, provides open learning materials for frontline workers and offers practical suggestions for how services might become more responsive to older families.

### **[www.doh.gov.uk/vpst](http://www.doh.gov.uk/vpst)**

The valuing People Support Team website is a useful source of information for family carer representatives. The website also contains details of regional network meetings for family carer representatives on Partnership Boards and subgroups organised by the Valuing People Support Team members across England.

### **Older Family Carers Initiative (OFCI)**

OFCI aims to support Learning Disability Partnership Boards to identify and meet the needs of older family carers of people with learning disabilities as prioritised in *Valuing People*, the Government's white paper on learning disability. The OFCI, a three year project led by the Foundation for People with Learning Disabilities, has produced these

guidelines to provide useful, good-practice information and ideas for supporting older family carers. They are intended as a tool to help Learning Disability Partnership Boards, commissioners and frontline workers across England reflect on the way that older family carers are supported in their area. They are also designed for older family carers, to inform them of their rights, the support they could receive and of the processes outlined in *Valuing People* that will affect them.

The Older Family Carers Initiative is led by the Foundation for People with Learning Disabilities in partnership with a range of organisations and individuals including BILD (British Institute of Learning Disabilities), HFT (Home Farm Trust), Valuing People Support Team, Housing Options, Carers UK and Mencap. It is funded by a Department of Health section 64 grant.

For more information about the Older Family Carers Initiative and to join the mailing list for *Family Futures* (Initiative newsletter) contact: Older Family Carers Initiative, Foundation for People with Learning Disabilities, 83 Victoria Street, London SW1H 0HW Tel: 020 7802 0329 Email: [fpld@fpld.org.uk](mailto:fpld@fpld.org.uk)

Other guidelines available in this series include 1,2,3 and 4. Please visit [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)