

Preparing for the Future

People with learning disabilities and their ageing family carers.

SUMMARY

The update reports on an action research project which aimed to identify how best to support older family carers and their relatives with learning disabilities plan for a transition from living together in the family home. It found that there are eight distinct stages to this process. Moving on takes time and sensitivity on the part of services and workers. The process must develop at a pace and in a way that retains the confidence of the family carers. Firm plans are only realistic where a move is imminent. Where this is not the case preparation work is still vital.

BACKGROUND

Since 1996 The Sharing Caring Project (SCP) has been leading the way in working with older family carers. The project workers have shown to acknowledge and respect the role played by family carers, and also to recognise the inter-dependent relationship which they have with their relative and therefore to balance different points of views between carers and their adult relatives. In so doing it has built-up trust with all of the key players: older family carers, their learning disabled relatives (supported by Sheffield Citizen Advocacy) and with agencies.

As part of the Growing Older with Learning Disabilities (GOLD) programme at the Foundation for People with Learning Disabilities, SCP was funded to undertake an action research project. Community Health Sheffield NHS Trust also financially supported the research. The aim was to identify the best ways to both help older families prepare for the future and make the inevitable transition from living together in the family home.

The longstanding neglect of people with learning disabilities and the older relatives they lived with has been highlighted in earlier research (Walker & Walker, 1998). In England this group has been identified as a priority in recent learning disability policy with the expectation of helping these families feel more confident about the future (DoH, 2001, Thompson, 2001).

THE RESEARCH

The action research project involved the following elements:

- Intensive individual case work with 25 families focusing on transition from the family home.
- Four family carers groups set up in different parts of Sheffield
- Interviews with family carers and people with learning disabilities where the individual had already moved away from the family home.

- Developing written information about planning for the future which was distributed to nearly 400 families.

External evaluation of the work was provided by Professor Carol Walker from the University of Lincoln.

THE FINDINGS

The project identified eight stages involved in supporting families to prepare for the future.

1: Thinking about the need to plan ahead

All the families in the project were at different stages in their readiness to plan for the future. Some families needed support just to get the right services in place to help them cope with the present before they could begin to focus on the future. All family carers said that they worried about the future and what would happen to their relative when they were no longer around. In addition, the relatives with learning difficulties were aware that their parents were ageing and that people do sometimes move on from the family home.

2: Openly acknowledging that change is inevitable

The project found that it can be very difficult for family carers and their relatives to move to planning for the future. Different people were able to move to this stage at different times and sometimes there is disagreement within families about the urgency of planning for the future. Having time for the workers to build-up trusting relationships with families was very important.

3: Information gathering

At this stage, people used different methods to find out how to plan for the future and what sort of options were available. SCP provided individual support, group support, written information and a Thinking Ahead video which had been distributed to key professionals working in the area and which used a case study to illustrate how a family could begin to plan for the future. Information about Wills and Trusts were also important here.

4: Identifying Needs

Although families needed to know and understand practical information about planning and options, this stage is the most crucial. At this time the needs of the person with learning difficulties and their family carer were identified with the project workers and then these were considered in relation to the local possibilities for accommodation, support packages and, most importantly, funding.

5: Agreeing the way forward

At this stage families needed to decide on their time-scales and priorities for moving things forward. For some families, health and age was a factor necessitating urgent action, but others could afford to wait. Stage five is the crossroads: families might choose to leave things until a later date, possibly undertaking further preparation (for example, setting up a Discretionary Trust), or were able to move on forward and begin to implement this major life change.

6: Addressing the practicalities

Once the decision to look at options for the person with learning difficulties moving on is made, then a number of practical steps have to be taken. This will include involving a social worker or care manager to secure a placement and funding. A full needs assessment of the person with learning difficulties is required. A carer's assessment at this time was found to be essential as it allowed the family carer's position to be clearly recorded and inform the decision making process. Some families were held back at this stage because of lack of funding. In many local authorities funding is only available when the home situation has, or is likely to, break down.

7: Moving

Once a suitable placement has been secured, the process of moving can begin. A gradual programme of visits and overnight stays should be introduced so that the person gets used to their new environment and the family carer can see whether they are settling in well. After a successful trial period then the permanent move can be made.

8: Continuing contact, support and involvement

When a family member moves out of the family home, the family relationship remains an extremely important part of everyone's life. Arrangements need to be made to allow contact to be continued between the family carer and their relative. Keeping in contact proved to be a vital part of helping everyone to adjust to the new situation. Although some individuals benefited from not going back to the family home for a short time to reinforce the point that their move was more than just a short respite break, others visited home regularly for weekends or overnight stays, and families visited their new home.

For those families where the person with learning difficulties had moved on, it was important for support for the family carer to continue. Otherwise they may feel abandoned to cope alone with the emotional burden, and guilt, of separation as well as having to deal with numerous practical issues including loss of money and help with household tasks. It is important to ensure that family carers remain aware of their right to be involved and consulted in reviews, meetings and social events involving their relative.

The needs of families were very different and work with families needed to be conducted at a pace and with a sensitivity which reflected their anxieties. When a planned move took place for one of the families involved, the whole process from initiation to move could take up to two years.

IMPLICATIONS.

- Before anything can be done about the future the family's current needs have to be considered and stabilised.
- Planning for the future is a highly complex and individual task – people have different needs and different capacities to cope. Families largely have to set their own pace.

- Much can be done to provide older family carers with the practical and emotional support they need to set in place processes which will offer greater peace of mind about the future.
- The process can take many years and will often be blocked by the unavailability of funding or suitable accommodation.
- Family carers do not stop caring when their relative leaves home and it is important for agencies to acknowledge their continuing role.
- Because of the many uncertainties about the future, not least the unpredictability of learning disability provision, it is better to work towards helping families prepare for the future rather to lay down too rigid plans.
- Local authorities need to ensure that there workers who have the capacity, both in skills and time, to support families with planing for the future.

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

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