

# Be Your Own Keyworker

## *Suggestions for a DIY approach to the adaptations process for disabled people and/or their family and carers*

This manual is intended to make the process of adaptations easier for disabled people and their families and carers. It is primarily for everyone with muscular dystrophy or an allied neuromuscular condition and the wide range of professionals trying to help them. However, it is hoped that the manual will be useful to a much wider audience.

Although some disabled people may prefer to take a less active part in the process, there are many of you for whom there is no better solution than being your own keyworker. No one will care more than you about the adaptations and decisions made to achieve the optimum result. This manual should help you from the outset to understand the whole process. Although time-consuming, it will put you in control of the stages to be worked through, from the first referral to the Social Services Department and the assessment procedure, to the completion of the building work. However, the whole process of adaptations can be very stressful and you must ask for help at each stage if you need it – and particularly if you feel bogged down by it all.

## Use the following 10-point plan

### 1. File correspondence

Keep all correspondence together. Many families experience reluctance on the part of advisors to put anything on paper. Therefore, always ask for important decisions to be put in writing and press for a written reply to any query. Copies of all communications keep the file up to date and make it easier to back-track if, for example, your trusted occupational therapist (OT) leaves and no-one else seems to know what is going on.

### 2. Record contact details

Record the name, address and telephone number of everyone involved. It is also useful to know on which days and hours they are at work, and when it is best to contact them (particularly as many OTs work part-time). A form is included for you to photocopy and use to record this information. File it with your correspondence.

### 3. Accurate diary recording

In the same way, photocopy the sample diary page or draw up your own. Make enough copies, punched to fit your file, to ensure that they are readily available. Use the diary as a simple means of recording the date and time that each telephone call is made or received, and every meeting held, in relation to the adaptations. Make an accurate record of the conversation and ask for an explanation of anything you do not understand. Ensure that you are given a time-scale (even if only approximate) for the completion of each stage and what happens next. This enables you to monitor the progress and check that the work is followed through by the appropriate person. If you are unhappy with the progress of the scheme, then your record of the dates of all the calls and meetings puts you in a strong position if you need to make a complaint.

### 4. Chase up outcomes

While acknowledging that all workers are trying to keep up with very heavy workloads, keep track of these time-scales. If they are not met, make contact to find out what is happening. Most workers will welcome a timely reminder.

### 5. Muscular Dystrophy Adaptations & Building Design Network

Where possible, use this scheme to find a designer who has attended a workshop about people with neuromuscular conditions, and has experience of planning for their disabilities and needs.

### 6. Want vs needs

The word 'want' always creates a negative response from workers in statutory services and should be replaced with the word 'need'. This is probably because of the wording in the Disabled Facilities Grant guidelines which states "... distinguish between what are desirable and possibly legitimate aspirations of the disabled person, and what is actually needed and for which grant support is fully justified".<sup>1</sup>

## 7. Outcome of the assessment

Always aim for the best but, if necessary be prepared to compromise on the less important items, if these can be funded with an additional grant (but no contribution) and included at a later date. The priority is space, as this is difficult to add on in the future.

## 8. Funding

Many schemes break down from the outset because of the emphasis placed on funding issues. Therefore, the needs assessment becomes overlooked. If you have to fund your own adaptations, the Local Authority still has a responsibility to provide advice. You must contact the community OT and ask for assistance.

The priority is to establish what is needed and only then to consider the funding problems. It may sound negative to talk about funding as a problem, but it is necessary to be aware that there are few schemes where it is not a problem. The majority of people experience similar difficulties.

## 9. Complete the adaptations questionnaire

It is important, for future schemes, that the Muscular Dystrophy Campaign learns from your experience. We would, therefore, be very grateful if you would complete the questionnaire included in Chapter 13, whether or not you have used the Muscular Dystrophy Adaptations & Building Design Network. This will enable us to monitor the standard of adaptations and plan services to families.

## 10. Pass on your experience

If you are able to master the process, your experience will be invaluable to others. This is the value of belonging to a Muscular Dystrophy Branch, as it enables disabled people and their families to benefit from the support of learning from each other.

## Reference

- 1 *Circular 17/96 Private Sector Renewal: A Strategic Approach, Annex I.* HMSO, 1996, pg. 198.