

## Case Example 4:

# Independent Living Programme - Stoke Mandeville Spinal Injuries Unit

**Type of organization:** Training programme at National Spinal Injuries Centre Stoke Mandeville Hospital.

**User group:** People with spinal cord injury going through rehabilitation (inpatient).

**Staffing:** One paid worker, together with a team of volunteer peer advisors and members of the unit's case management team.

**Funding:** The programme is funded by Stoke Mandeville spinal injuries unit.

### Overview:

As part of a wider Patient Education Programme it aims, through four two-hour sessions:

- To encourage participants to think how care will fit into their lives post-discharge
- To help them understand the funding streams available to them
- To consider different models of employing Personal Assistants (different agency and voluntary sector options, employing people directly, and so on)
- To begin to draw up a daily care plan (entails thinking about what things participants will need support to do, and how best this can be achieved)

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## Evaluation

The programme has had some positive feedback from participants, but no formal evaluation has been undertaken.

## Features of Good Practice

### Person-centred ways of working

People with high level spinal injuries can find themselves suddenly dependent on a high level of support. The programme helps them to imagine what their life will look like post-discharge, and think about how they can use care to facilitate the life they want. The programme emphasises that care should fit around people's lives – their lives should not have to fit around care.

### **Meeting practical, emotional and social needs**

The programme demystifies the realities of living in the community with a care package and addresses people's concerns about issues like relationships, security and confidentiality. It also focuses on how care can fit with family life, particularly in terms of partners, private space, children and parental roles.

Helping people to begin the process of drawing up a care plan, and writing it down, has a number of advantages. It encourages people to start to understand what care they will need and the implications this will have on their lives. This is a powerful tool when dealing with funders and the assessment process, as people can be very clear about their needs and how they would like these met. If the resource allocation system gives an indicative budget that is unrealistically low, people are in a position to challenge this.

### **Help to access and use information**

The programme empowers people by informing them about how the social care (and to some extent continuing healthcare) systems work, focusing on broad principles, such as what to expect in the assessment process, and who should be involved.

The course also provides information about the pros and cons of different options for support, and tips for using them. It gives people ideas of the questions to ask agencies, and of the issues surrounding employing people directly. Having information about what agencies should be providing puts people in a good position for negotiating with them.

The involvement of peers means information is grounded in real life experiences. The course also gives people insight into the resources that are available at Stoke Mandeville and other rehabilitation units, and encourages them to take advantage of these.

### **Specialist expertise**

The programme is delivered by an Independent Living Consultant who has a spinal injury himself and has been living with care for 17 years. Peer advisors are all people with spinal injuries living with care in the community. They are a mix of men and women of different ages in different circumstances, ranging from those who receive 24-hour support packages to those only receiving spot care.

### **Further Information**

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