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## 8 Information for Younger People Moving into Residential Care and for People with Learning Difficulties Living in the Community

The following points emerged from two group discussions. The first was with four residents of a voluntary sector home. Two of the residents were in their mid 20s and were almost completely paralysed as a result of motorbike accidents. The other two residents were in their mid 40s and had multiple sclerosis.

We asked the group whether they had received information from various professionals and organisations with whom they might have come into contact, and how useful such information had been. We also asked them if they had tried to find any information for themselves and how they had gone about this. Finally, we asked them to review their experience of moving into residential care and to give their opinions about the amount and type of information that should be provided to people in those circumstances.

Two of the residents had come to the home straight from hospital. Another had been a patient in a hospital and the hospital social worker had maintained close contact after his discharge. Hospital social workers had been important sources of information to all of them, although this was likely to be in the form of referrals rather than factual information about homes. One person said the hospital social worker had referred her to CareMatch. Another said:

Because at first I'd had no idea of where to go or what to do, so she gave me guidance, but she was not useful in that she didn't really give me any information.

Another person mentioned that the hospital social worker had told her that certain services, which might have enabled her to live at home, were not available in her area.

In some cases the information seems to have been inaccurate - two of the residents said that hospital social workers had told them there would be no problems with the financial arrangements but in fact it had taken years to sort things out.

The residents had all had contact with consultants during their time in hospital but they do not seem to have been important sources of information. One of the group did say that the consultant was:

... the first and only person to talk to me, in hospital.

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It seems to be usual for the consultant to expect the hospital social worker to provide information to the patients.

One of the group had discussed the options available to him with the district nurse and found that he had a good knowledge of the facilities available locally, but not beyond the local area.

Social workers were far more important as information providers and all four had been in contact with social workers. However, they all felt that the social workers could have been more forthcoming with information about the home before the actual move was made. This information should ideally be based on visits to the home by the social worker.

Lack of such personal knowledge by the social worker made visits to the home before moving in even more important. All of the group members had found the visit to the home and the opportunity to talk to the manager and his deputy very useful. They welcomed the system, recently introduced, of new residents meeting representatives from the clients committee before moving in. One of the residents said she would have liked to have the brochure about the home before she moved in, but did not get it till after she arrived.

Three of the group felt that information had not really been an issue for them at the time of their move because it was made very clear to them that there was no alternative. One in particular said he had felt pressurised into making the move because there was an NHS contracted bed available in the home and everything had happened very quickly. Had there been any choice available, documentary information would have been useful, because it is very difficult for physically disabled people to get out of hospital and visit different homes.

The fourth member of the group had previously been living in the community but his carer was no longer able to care for him. This had been recognised in plenty of time and he had time to gather information and decide what to do. He had explored the possibility of living in the community but it was impossible financially.

The manager of the home pointed out that the situation was different now - he did not feel that everyone would assume that residential care was the only option as they had done when these people were moving in.

The second group discussion was held at a day centre for people with learning difficulties. The scope of the discussion was limited, consisting of responses to four questions which had previously been distributed to the group.

The group was asked if anyone had talked to them about what going to the day centre would be like. Six people mentioned a social worker, four mentioned parents and three mentioned school. The workshop and the hospital were each mentioned once. However it was apparent from the answers that were given that in many cases no clear distinction was being made between who gave information, who made the arrangements and where they were previously.

The next question concerned the clients' expectations about the day centre - had it turned out to be like they had expected? Two of the clients said it had, while one had been before and said that it had changed in that there used to be workshops.

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One of the clients who said the centre was like they had expected also mentioned that they had had to work on the first day. Otherwise, two of the clients said they had liked the centre from the first day while one said that it had felt strange and they had been scared.

In response to the question 'who do you talk to about the centre?', half the clients mentioned their parents. Brothers and sisters were mentioned three times, friends at the centre twice and other friends once. Staff at the centre were the main formal contact, with four mentions, the key worker was mentioned twice, and teachers and People First once. One of the clients talked to 'whoever is around'.

Finally, clients were asked what they would like to know if they were going to move. Most of the clients just mentioned one thing, such as 'If it was friendly' or 'If it was big - I like being in a smaller place'. However, some had more extensive requirements:

I should want to go and see it, see how it is run, before I decided. The ins and outs - rules, type of food.

Do they watch TV there, can you listen to the radio, do they go to bed early, get up early and go to work.

Overall, information about work, regulations, and how friendly it would be featured most prominently, each being mentioned by three clients. Food was mentioned twice, and there were single mentions of what the staff were like, being allowed out at weekends, sleeping arrangements, the size of the home, access to television and radio, and wheelchair access.