Where do you want to go next? Newsletter and summary

Local authorities should concentrate on providing access to and increasing the number of people who live in their own homes or have assured tenancies in rented accommodation.

(Valuing People Now, 2007: 8.2.1)

The South West study

In 2004, two out of three adults with learning disabilities living outside the family home were in residential care[1]. But we know this is not the best way for many people to live. Valuing People Now[2] for instance has a priority to provide more choice for people to have housing which suits their needs. This includes supported living, where people may be tenants or home owners.

When people with learning disabilities want to move, they often go to a care manager. The care manager's job is to make sure they have the things they will need, and find a good place to live.

- Sometimes people move into residential homes.
- Sometimes they get a flat or a room, and support staff to help them (supported living)
- Some people stay at home, and have things to do during the day.

We did a small study, funded by the South West Centre of Excellence [LIFT SW], to find out what things led to these different results. We looked at records of 28 people with learning disabilities who had a care plan in 2006/7 in four areas in the South West. We also interviewed their care managers. 10 of those had gone into residential homes, 5 did not move from the family home, and 13 moved into non-residential situations.

Who moved into supported living or residential care?

Of the 28 people in this study, those who had fewer needs for support were more likely to move into 'supported living'. Having families and other people who spoke up for you also helped; 6 people had a person-centred plan (PCP) on file, and 5 of those moved into supported living, so it seems that a PCP can help people get more choices. But there were another 4 who had started a PCP with their families which was not in their social services file.

Cost did not appear to have an influence on where people moved; it was more to do with individuals' needs. On the whole, families did not push for residential homes.

All those over 50 moved into residential homes. This might have been because they had greater health needs.

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[1] Emerson et al: http://valuingpeople.gov.uk/dynamic/valuingpeople9.jsp

[2] http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_081014

Costs

We found out how much it cost for people to move into different places. The costs of most of the residential packages were in the range of £1,000 a week, with a high of £2,066. Supported living was cheaper, with 11 people costing less than £1000 a week. The mid price for supported living was about £650 a week.

People with higher levels of support need cost the most, wherever they lived. Some people with very complex needs stayed at home with parents, and one of these people's package cost over £1000 a week. But most people living with parents cost social services much less. On average, these families were saving the state about £500 a week.

There was some limited evidence to suggest that the people who went into supported living would have cost (on average) £123 more if they had gone into residential care homes. But no-one's move had been turned down because it was too expensive.

Apart from other benefits, there are good cost reasons to move towards supported living. We estimated that one person could move into supported living, and another one get support at home for the same cost as one person in a residential care home.

Choices

When you want to move, you need to know what your choices are. But we found that it was hard to get clear information about the options. When there was a place free in a home, for instance, care managers told each other. They sometimes sent parents to look at different places, but people with learning disabilities themselves were often only told about the choice once it was more or less fixed.

Care managers were often still unclear about individual budgets, and how they should work these out for individual clients. None of these 28 people had a direct payment for support in their own home.

Where had people been before they moved?

14 of the people we looked at were moving on from the family home. Only 2 of those moved into residential care. People were far more likely to move into residential care if they were already outside the family home (in another home, or at college).

Where people had been to residential college, families had already made the break. However, families often put in a lot of work to plan a life for their young person at the end of college. Although college staff helped people think about the future, it was hard for them to make practical links with the home area.

In summary, what helps people get more choices?

- **A person-centred plan**
- **Families who advocate for them and help put plans into action**
- **Getting good information**

What did people with learning disabilities and their families tell us?

> ***'I can do my own stuff – cooking washing. I have a rota for my living skills. Before, I lived with my parents and they did everything for me. Now I'm happy with people my own age. The staff are friendly and helpful. I enjoy doing things for myself, and I am an independent traveller.'*** [Person with learning disabilities]

We went to see 12 of the people with learning disabilities and their families at home.
People in supported living mainly said they liked their new life, especially the staff and having more independence. But one person was quite stressed, and others were worried about seeing their parents. They still talked about their family house as 'home', and they sometimes missed old friends.

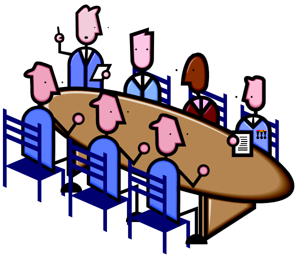
'I had a friend called Ellie. She was funny. She made me laugh a lot. I don't know what she is doing now.'

Having a voice

7 of these 12 people had a person-centred plan at some stage, and families had often helped them by getting other friends involved. 3 of them had advocates, although this was not successful in one case. But it was still hard for people to really speak up about what they wanted. Decisions were often made for them in their best interests. Parents often found practical ways of involving people in decisions:

- They took their son or daughter on visits to see a choice of new homes
- Sometimes the only way you can tell whether something is going to be a success is to 'try it out'

Many people show their choices by their reactions to people and places, and '*over the years we know what he likes and doesn't like.'* [Parent]



People with learning disabilities hadn't always been included in meetings about their move, and parents felt this was wrong.

Working with parents

The three key demands from parents were:

- Information
- Action
- Communication

'Communication is the key. How do carers find out what the options are? And that's where social services could take a much more active role.' [family member]

Some of the parents we met had been very active in sorting out new choices for their son or daughter. Social services praised these parents, and relied on them. But there were three cases where the social worker felt the parents' interests were in conflict with those of the young person.

Getting to know each other

'My social worker listens quite a lot. He is very talented, makes me laugh. I think he is useful, helpful, trying to help.'

People with learning disabilities and their parents said that the relationship with the care manager was all important. It helps to really get to know the person. Care managers felt that too, but said that it was very hard to have time to do that for everyone.

Information

Families told us how difficult it was to find out what was available. Many had found out about options through friends or other family members, and said it was very useful to have good examples of what had worked for others:

'She was able to talk from a personal viewpoint. It helped that it was another parent. She was extremely good.' [Parent]

From the care managers' point of view, though, the biggest factor in moving was to find a place that was available. The information tended to get shared between care managers, as this person said:

'To be honest, in a town this size, it's word of mouth' [care manager]

'21st century vision from the top'

When asked what made the most difference to them, families said they wanted social services to work *with* them, and to give good, creative leadership. Care managers also praised good leadership:

'The managers are owning the problem, they see it as their problem…It's about 'we have an issue, we've got to come up with a solution.' They're backing us, you're not constantly pushed back.' [Care manager]

The messages for good practice from these case studies were:

- Listen to the person with learning disabilities
- Work with families
- Get to know the person with learning disabilities
- Ensure good leadership and vision
- Provide open and clear information about the options available
- Judge satisfaction with outcomes
- Help people with learning disabilities keep in touch with old friends and contacts.

Fictional stories typical of those in this study

Leila is a young woman of 23, who has been at residential college. Previously, she had been at a special school where she stayed until the age of 19. Leila is extremely sociable, although she has limited speech. She is also prone to some odd behaviours, which those around her have found quite challenging. These include running away, and screaming loudly without any warning. Her family consists of a single mother, and two older siblings who keep in touch and see her regularly. One of them is very supportive, and has started university training in health and social care. She has told Leila's mother about what she is learning – and introduced her to documents such as *Valuing People.*

Leila's care manager, in the meantime, has been visiting Leila for her annual reviews at college. However, he founds her quite hard to get to know. He has talked with her mother on a regular basis, but does not really understand the extent of Leila's challenges. He also has very little knowledge of what Leila herself might really want after college.

At the last review at college, both Leila's mother and her care manager were shocked to hear that the college placement was no longer going to be funded. She had been expecting to access a fourth year in college, but now she was suddenly due to return home. Leila's mother had recently started working, and needed to keep up her job. She was very anxious that Leila should not simply return to the family home.

The care manager found out lots of information about possible placements for Leila in her home town. In the meantime, Leila's sister encouraged her mother to look more widely, and they visited a supported living house which had been recommended by the college. Two of Leila's college friends were already living there, and Leila's sister suggested that Leila herself should go and visit. Immediately, she appeared to be very happy there, and was pleased to see her friends.

Leila's mother argued with the care manager, and put her view across that the supported living placement was the best for Leila. In the end, she won. It was not a cheap option, but it appeared to meet Leila's needs. At the end of the summer holiday, instead of going back to college, Leila went into her new home. She herself still expects to be going back home, and she is wondering right now why she is having such a long term. She also misses friends she used to see who live near her home. However, in general, she is still happy with her friends, and is being encouraged to learn new skills. For her, it is an extension of college life.

Leila at college – but still in close touch with family

Wider family involvement – still developing. Finding out about Leila's rights.

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Care manager College reviews + talk to family

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CRISIS POINT

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Mother Leila not returning home

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CM: Local options

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Sister talked to college and found SL house

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Leila visits

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Mother argues for that option

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Leila moves

Marcus at home, likes pub and has local community connections

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Leaves school, no options for FE

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Care manager Offers direct payment: now **Marcus** has support workers

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Mother and care manager start process of person-centred plan

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Marcus has a plan to say what his goals are

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New housing project starts: local, and moving towards M's goal

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Family visit and say yes

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Marcus moves

Marcus is a young man who has multiple and complex needs. He has a physical impairment, and uses a wheelchair. He has very little verbal language, but can show pain or displeasure, as well as pleasure, by his facial expressions. He has a very loving family, who have always cared for him and encouraged him to learn new skills and to enjoy community activities. He loves to go down to the pub with his father, and many local people know him well.

At the end of Marcus' school life, there do not seem to be many options for him. Unlike some of his schoolmates, he is not considered suitable for the local FE college, and the care manager discusses with the family other options for specialist colleges which are quite distant. Marcus' family does not like the idea of him moving away, and they choose to carry on with him at home. However, a direct payment is put in place, so that the family can help Marcus get support workers who will help him to have some daytime activities. Now he goes regularly to the local leisure centre, and can go to the pub without his father hanging around!

Marcus' mother and his social worker think it would be useful to put in place some longer-term plans for his future, and they start to think about how a person-centred plan might help. A facilitator is found, who is a friend of the family, and can help get people together who know Marcus well. Marcus himself goes to the meetings, and people from the local pub also come down to his house. They all share their views on what Marcus likes best, and they think about what his future will be like.

Now Marcus has a plan which states that he wants to move into his own flat, to live quite near his parents, but to have some good support workers who like to go bowling, and are relaxed and friendly with him. His care manager talks with the family about shared ownership, and they work out a plan for Marcus to move into his own flat locally. At the same time, a local project has been set up which aims to bring together a group of young people with multiple needs. They will each have their own flat, and can live there with independent support providers coming in to assist them in daily living. The project is intended to provide a stepping stone for these young people towards independent living, and Marcus' parents go there to have a look with him. They feel this is a safe and exciting project, and that they have nothing to lose by allowing Marcus to try it out. This is now where Marcus is. He still has his longer-term goal, and the people who helped him with his person-centred plan are still in touch and go to see him regularly. Marcus is doing very well, and his parents are happy that he has settled there happily.

Jenny at
home and
local college

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CRISIS
point

Grandma
helping out

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Care
manager
called in

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Short break
carer

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Advocate

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Residential
home place
is free

Local, near
college,
young people

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Care
manager
and father
decide.

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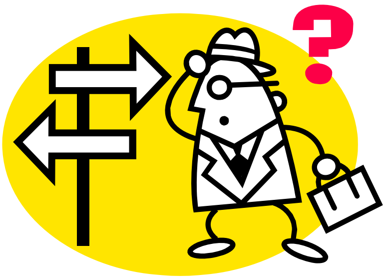
Jenny's
advocate
visits with
her
Jenny moves

Jenny is a young woman with Down's Syndrome. She is lively, enjoying drama at college, sports and any activities involving other people. She has done more than one work placement, and loves hotel work and catering. She would dearly love to have a job and earn money, just like her sister does. However, she is considered to have challenging behaviour, as she can become very angry and frustrated at times. She has self-harmed on occasions, and she also attacks those around her when she can't have her way immediately.

One day there is a crisis. Social services receives a call to say that her mother has been involved in a car crash, and her father can no longer keep Jenny at home. The grandparents are 'baby sitting' for her, but this will only be a temporary solution. Jenny herself is naturally very upset, but is clearly stating that she does not like being with her grandparents. She wants to see her friends, and she hasn't been into college since her mother's accident.

Her care manager had not seen Jenny for many months before this crisis, She was not considered to be a priority for care management. However, she now becomes an 'emergency', and the care manager goes immediately to see what he can do for Jenny. Luckily, there is a local placement for short-term breaks which Jenny had used in the past, and he suggests that this might be a good option for Jenny to try now. It is not intended as a 'solution', but at least it will solve the problem for the time being. While Jenny is there, the care manager also manages to get her an advocate from the local advocacy service, and Jenny gets on well with Lucy, her new advocate.
Jenny's father visits her at the short-break home, and says that he is very pleased at how well she is doing.

The care manager hears that a place has become available at a local residential home, which specialises in 'challenging behaviour'. He goes to have a look at the home, and thinks that it would be very suitable for Jenny. It is near to her college, and has good links with the college and with the local community. Staff appear to work with residents very well, and there is good support for younger residents in particular, who join community groups and have a variety of activities. The care manager talks to Jenny's father, as her mother is still in hospital. Jenny's father also thinks the residential home will be a good idea, and the care manager tell him that he is very lucky a place has become available at just this time. They decide to go for it, and Jenny herself is taken to the house to have a look, along with Lucy her advocate. Jenny sees someone there whom she knows from college, and so is quite happy to go inside and look around. A moving date is planned for two weeks' time, and Jenny goes straight there from her temporary placement.



Main messages

- The top managers in social services need to have vision. They need to encourage individual budgets and creative ways of thinking about support.
- They should make sure people get person-centred plans, and they should listen to those plans.
- Care managers should always ask families and people with learning disabilities if they already have a person-centred plan, and whether they can use it for care planning.
- Care managers have to work with other organisations, so that people get more choices and better information about supported living, shared ownership, renting, group living.
- There is already a regional database of providers. Social services ought to use this better, and flag up vacancies.
- Social services should make accessible information about housing options for people with learning disabilities.
- Social services should work with families, and give them good information. Families will be good advocates for their son or daughter.
- People who are moving on should also get independent advocates.
- Social services needs to carry on visiting and making sure the person with learning disabilities is happy, once they have moved. It may also be good to have an advocate then.
- Social services need to work out individual budgets. They can do this with the fair pricing tool.
- Care managers and finance departments need more training in working out finances and individual budgets.
- People with learning disabilities are all different. They want a range of different things in their lives. They should not just be slotted into the things that are there.

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