

Where do you want to go next?

Critical factors in care planning for people with learning disabilities, and their financial implications

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Executive summary

- This study aimed to explore the factors which are associated with different outcomes of care planning for people with learning disabilities. In particular, it explored the differences for those going into residential care, and those who had a supported living placement, or some other community-based option.
- The study took place between 2006-7, and drew 28 cases from four social services departments in the South West of England. Ten of these had residential outcomes, and 18 had supported living or other outcomes.

Findings

- ,People who received residential care placements were more likely to:
 - have a larger number of support needs recorded
 - be amongst the oldest group of service users
 - not be moving from the family home
 - not have a person-centred plan taken into account
 - have previous high levels of support supplied
- Those who did not go into residential care were more likely to:
 - have a lesser number of support needs recorded
 - have parents or family members who advocated for them
 - have a person-centred plan which was taken into account in care planning
 - have previous support arrangements of less than 24 hour care.
- Cost did not appear to have an influence on the choice of residential placement, whereas individual need nearly always influenced the choice. On the whole family pressure was not a reason for residential placements.
- People with higher levels of support need were costly to place, whatever the type of accommodation. However, this study delivered some evidence that the cost of residential packages was higher than the cost of providing community-based support. In broad terms, the cost of providing residential care for one person was the equivalent of one person in supported living + another staying at home with support provided.
- Information about available options for housing was very limited, and often 'covert'. Care managers often did not have systems for sharing information openly with families and service users.
- Care managers were often still unclear about individual budgets, and how they should work these out for individual clients.

- For those moving on from residential colleges, it was hard to provide a smooth transition back to the local area. However, families were more 'decided' about moving on in these cases and college staff were often active in supporting the young people to plan for the future. Ways to keep up links with college staff and friends would be very valuable for the young people in their new homes.

The messages for good practice in care management, from twelve case studies of outcomes were:

- Ensure good leadership and vision 'from the top', with management that encourages open discussion of individual budget and direct payments options, together with creative ways of thinking about support packages.
 - Ensure a person-centred plan, and take it into account in care planning
 - Routinely ask families and individuals about the existence of a person-centred plan, and for their permission to use it in care planning.
 - Work in partnership with providers to offer a wider range of options (including supported living, shared ownership, renting, group living), and to make information on this more widely and openly available.
 - Make better use of the regional database of providers, in order to flag up vacancies.
 - Make accessible information about housing options available to people with learning disabilities themselves, and encourage them to pursue these options – to visit and discover for themselves what they would like.
 - Work with families, ensuring they also have good information, to release the potential for good support and advocacy.
 - Ensure independent advocacy for people with learning disabilities who are moving on.
 - Judge satisfaction with outcomes by continued work alongside the person with learning disabilities, if necessary through an advocate.
 - Use tools which are available for working out individual budgets for service users.
 - Create more training and support opportunities for care managers in financial planning and use of the fair pricing tool.
 - Use direct payments and IB flexibly, in order to develop a range of different lifestyles for people with learning disabilities.
- **The key recommendation** for further development is to improve the use of tools for working out individual budgets. Care managers need further training and support in financial planning and they need to learn how to make best use of the fair pricing tool, and resource allocations developed by 'In Control'. Refresher training is also needed around direct payments. This could usefully be done jointly with finance managers in SSDs, so that there is a full understanding of how to use direct payments and individual budgets flexibly, in order to develop a range of different lifestyles for people with learning disabilities.

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1. Background and introduction

This project was initiated by the Directors of Adult Social Care in the South West, because of concern about differential patterns in the use of residential care for people with learning disabilities. This is a crucial issue, of national relevance, highlighted by Cattermole, (2007) in '*A Tale of Two Nations*'. Government policy firmly recommends social services departments (SSDs) to move towards individual budgets, community options, and mainstream services (DoH, 2006), and Learning Disability strategy (DoH, 2001) has repeatedly supported SSDs to offer a wide range of choices, so that people with learning disabilities can have greater control over their own lives, in the most 'inclusive' way possible within their own communities.

However, a large proportion of people with learning disabilities across the UK still live in residential care homes. The 2004 survey by Emerson et al. showed that about half of all adults with learning disabilities were still living at home with parents, and a further 12% lived with other relatives. Of the remaining who lived outside the family home, nearly two out of three (62%) were living in residential care, as opposed to 11% in supported living schemes.

Residential care (as opposed to supported living) is associated with service users who have higher levels of support need; low levels of communication ability; challenging behaviours (Mansell et al., 2002). Felce and Emerson (2001) in a review of the literature on residential care, reported that

- People with more severe learning disabilities are prone to leading lives of under-occupation and low community involvement
- Ordinary housing stock and normative architecture are to be preferred
- Smaller size of residential unit is not necessarily better than larger numbers (within the range of numbers in an ordinary household)
- Either over-staffing or under-staffing can be bad
- The most important factor associated with increased engagement from residents is staff behaviour. Staff training has thus been shown to be the critical factor in improving outcomes.

In some areas, a large proportion of placements of people with learning disabilities are from out-of-area. Beadle-Brown (2006) for instance, found that about 1,400 people (between 30-50% of all placements) are placed in Kent from elsewhere.

The impetus in recent years has been towards 'supported living'. Emerson et al (2001), comparing supported living with residential accommodation, found that people in supported living had more choice; greater number of community based activities (compared with small group homes). Supported living was intended to be a model that decoupled support and housing (Simons, 2000: 8), and provided people with learning disabilities with choice, control and the status of being a tenant. However, Fyson et al. (2007) have recently found that supported living can sometimes be indistinguishable from residential care, in terms of service user outcomes.

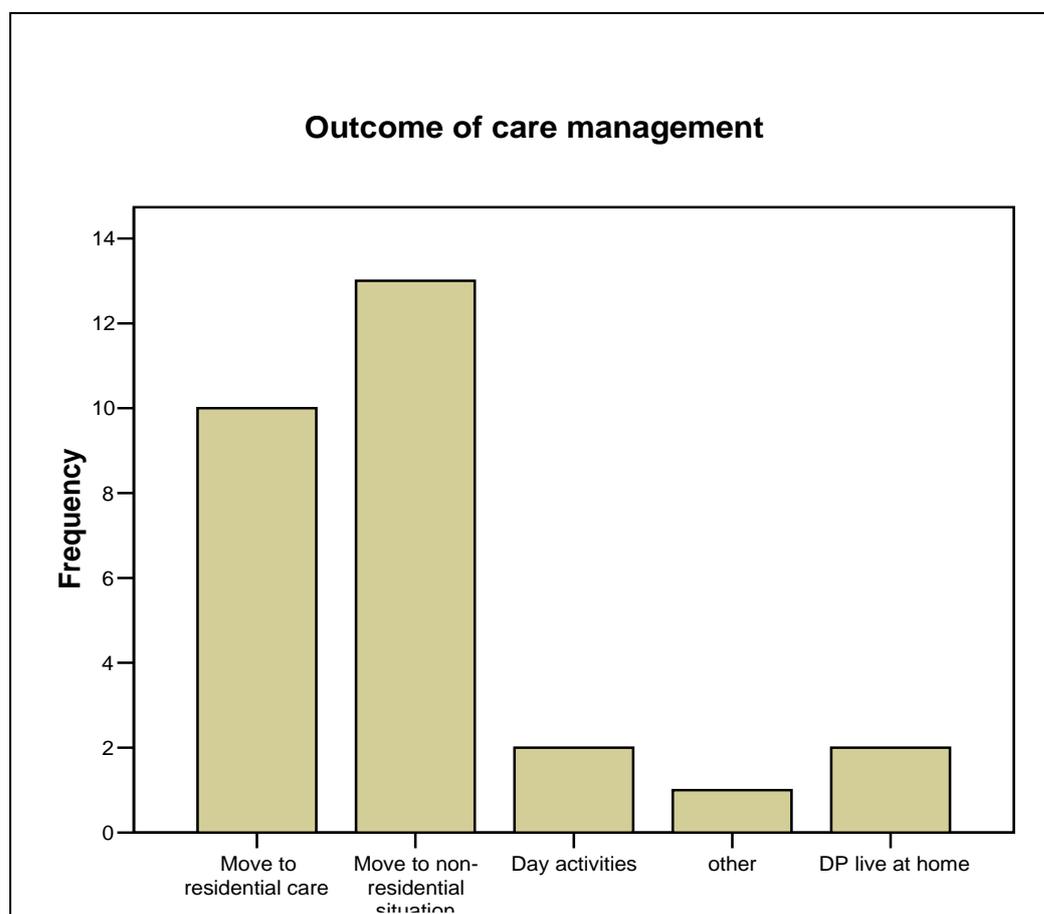
In the meantime, other models of residential care have continued to flourish, including moves towards village communities, or 'campus' provision. Hallam et al. (2002) carried out a cost analysis to examine comparative costs of supporting people in village community settings, NHS residential campuses and in dispersed, community based housing schemes. Wide variation in costs was found, with higher costs being associated with people with higher support needs and challenging behaviour, whatever the setting. On the whole, however, smaller facilities were likely to be more expensive. Emerson (2004) compared outcomes for those in clustered housing, with dispersed housing, and found a number of negatives for the former group, including lower staff ratios, greater likelihood of physical restraints, and less community involvement and social opportunities.

Finally, the move towards using ordinary community services and activities is starting to be matched by increased personalised support (Beadle-Brown, Williams et al., 2007). Support workers, or personal assistants, can be supplied by organisations or agencies; they are also purchased directly by individuals in receipt of direct payments (Williams, 2006). These options mean that some people with learning disabilities are able to carry on living in rented accommodation, or to purchase their own home through shared ownership arrangements. Others may be enabled to continue to live at home with parents, with one-one supporters to help them access activities outside the home. Research generally indicates high levels of satisfaction with these models of support, although we know that availability of staff and training are key to success (Mansell et al., 2002; Flynn, 2005)

In this context, little is known about the processes whereby people with learning disabilities come to be placed in these varied forms of housing and care. Research has repeatedly indicated the anxieties of carers (Williams and Robinson, 2001); lack of information, particularly at transition (Heslop et al., 2002; Tarleton et al., 2004) and the confusion of people with learning disabilities about the process of care management. There is a real need to look in more detail at how care management presently works, and what factors determine the outcomes for people with learning disabilities.

direct payment to cover some support for their day activities. A summary of the outcome data is shown in Table 2 below.

Table 2



Data from the record searches were mainly numeric, and were analysed using SPSS, in order to investigate the relationship between different factors in the care planning process. Data from all the interviews were tape recorded, transcribed, and analysed thematically. The sets of interviews (care manager, carer, service user) were triangulated on a case by case basis.

Section 3 of this report will first present descriptive findings from the numeric data, in order to explore the factors at play in residential, as opposed to non-residential outcomes. Section 4 will then present the data on comparative costs. Section 5 then goes on to discuss the themes arising from the 12 case studies, which will give a more in-depth view of outcomes and issues about care management. Finally, Section 6 presents some findings specifically about the sub-group of people with learning disabilities who had moved on from residential or specialist colleges. Section 7 offers some concluding remarks and recommendations. The methodology for the study is presented in greater detail in the Appendix,

3. Factors associated with placement in residential or non-residential care

3.1 Factors related to the individual

Below the age of 50, age was not found to be associated with particular types of placement; however, it should be noted that those over 50 *all* moved into residential care. This was because they had been referred for care management because of increasing physical needs, due to ageing. Another factor, of course, is the availability of family carers. An older age group does not have the option of living with parents.

For all individuals, we noted the support needs recorded in their care assessment. When needs alone are considered (without any other variables), no single need was appeared to be associated with going into residential care, although those with mental health needs were less likely to go into residential care than other people. However, needing support at night was linked with residential care (6 out of the 10 moving into residential care needed waking nights, compared with 4 out of the 18 non-residential). As the number of needs rises, so does the likelihood of moving to a residential placement.

Table 3: Residential care associated with level of needs of service user

	Total number of needs banded			Total
	1-4	5-6	7-9	
Move to supported living or stay in parental home	7	9	2	18
Move to residential care	2	3	5	10
Total	9	12	7	28

There was a strong tendency overall for care managers to attribute the key factor in decision making to an individual's needs, with the second most common attribution being 'family pressure'. They seldom said that any decision had been made on the basis of cost. Family factors or other reasons appeared to figure less prominently in residential care placements than in other outcomes (see Table 4).

Table 4: Residential care associated with the chief factor in the final decision

	Final decision about package			Total
	related to persons needs	related to family pressures	mixed, other, don't know	
Move to supported living or stay in family home	7	8	3	18
Move to residential care	8	1	1	10
Total	15	9	4	28

When combining variables that were fixed before any move to the next placement (age group, gender, previously living at home or not, number of hours of previous support, number of needs) the most important variable was the number of needs. Those with a total of 7-9 areas of need were 18 times more likely to move on to a residential placement.

3.2 Factors related to care planning

Care planning is intended to be a way to assess individual need, and to enable the individual to have a voice in determining his or her own future. In that respect, person-centred planning has been a strong theme since Valuing People (DoH, 2001). Six of our participants had a person-centred plan on their file (or had it referred to in their file), and five of those had moved to supported living or other options.

However, carers or family members told us of a larger number of PCPs than were apparent from the files. There were an additional 4 cases in which a PCP had been carried out (but where the care manager did not appear to know about it) out of our sample of 12 case studies. If this is the case overall, then we could assume that perhaps half of the total sample of 28 would have had a PCP at some stage, even if it was not apparent from their service records. It is interesting to note that 2 of the 4 'hidden' person-centred planners actually moved into residential accommodation. Although the numbers involved are too small for significance, this may indicate that care planning needs to take more account family-centred planning which has been attempted.

Table 5: Person centred plans and residential outcomes

	Residential outcome	Non-residential	Total
Person centred plan did exist, and taken into account in care planning	1	5	6
Additional PCP's that we found out about in the 12 case studies	2	2	4
No person-centred plan	7	11	18

The number of people consulted during the care planning process also appeared to have an effect. Where 4 or more people were involved in the decision, there was a 2:1 chance of moving into supported living, or some other option. This may well be an indication that the individual already had a wider support network, thereby making supported living more feasible.

3.3 Factors related to previous arrangements

Those who had previously not been living at home were 4 times as likely to move to a residential placement as those who had lived at home. Of the 14 people living at home with parents or family members, only 2 moved out into residential care, compared with 8 of the 14 living outside the family home. As Heslop et al. (2007) noted, residential FE placements should only be used as a last resort, as there is a strong tendency for young people to move from one residential placement to another residential placement.

Table 6: Outcome of care planning associated with previous living situation of service user

	previously at home	previously living elsewhere	Total
Move to supported living or other option	12	6	18
Move to residential care	2	8	10
Total	14	14	28

If a person's previous support was *not* 24hours a day, they were less likely to move into residential care. However, this is not surprising, given that we know people with a higher number of needs identified are more likely to go into residential accommodation. It is also worth noting from Table 7 that four of the people who did move into residential accommodation had previous support needs of less than 24 hours care. Two of these were older people who had deteriorating health (as was noted above, older people in this situation were all moved into residential placements). The remaining two were young people, one of whom moved into a residential placement as a 'temporary' measure, waiting for the right local arrangement to become available. The final one was a young person who moved into a MENCAP house because his older parents wanted him 'settled'.

Table 7: Outcome of care planning associated with previous support provided to service user

	24 hour care	Previously in receipt of care for less than 24 hours	Total
Move to supported living, or other option	3	15	18
Move to residential care	6	4	10
Total	8	20	28

Those who had been coping with lower levels of support were far more likely to be considered for supported living or other options.

3.4 Factors related to cost

Relative cost seemed to have little influence over choice of residential or non residential care. A few care managers were nervous about taking ‘high cost’ packages to funding panels, but there was no package in this study which had been turned down on the grounds of cost. Additionally, there was little relationship between the cost of the previous package and whether a person went into residential care. There were only 15 of the 28 cases in which the costs of the previous package were known. These are represented in Table 8 below.

Table 8: Outcome of care planning associated with relative cost of previous support package (as compared with the present package)

	Previous cost compared with cost of present package			Total
	About the same	Previous was more	Previous was less	
Move to supported living or other option	0	2	7	9
move to residential care	1	1	4	6
Total	1	3	11	15

In summary, people who received residential care placements were more likely to:

- a) have a larger number of support needs recorded
- b) be amongst the oldest group of service users
- c) not be moving from the family home
- d) not have a person-centred plan taken into account

e) have previous high levels of support supplied

Those who did not go into residential care were more likely to:

- a) have a lesser number of support needs recorded
- b) have parents or family members who advocated for them
- c) have a person-centred plan which was taken into account in care planning
- d) have previous support arrangements of less than 24 hour care.

Cost did not appear to have an influence on the choice of residential placement, whereas individual need nearly always influenced the choice. On the whole family pressure was not a reason for residential placements. On the contrary, family pressure more often worked in the opposite direction, as will be explored further in Section 5 below.

4 Cost analysis of final outcomes

The cost per week of the final care package for each case was recorded from written information, and confirmed through care manager interviews. In addition, we wanted to have a means of comparing all the cases against a common ‘needs’ based indicator of cost, and for this purpose we used the Fair Pricing Tool (FPT), which has been introduced in the South West to assist SSDs in negotiating prices of residential placements. On entering the needs of each person for support, the tool essentially shows what a fair price for that person would be, if they were in residential care. Of course, not all our sample were accessing residential care. However, we asked care managers to enter each case on the FPT, in order to obtain an indicative price based on the person’s level of needs. This process helps to compare outcomes, without undue bias due to the different levels of needs of individuals in the study.

Table 9: Comparative costs per week

	Mean cost £	Median cost £	Range £	Mean price indicated by FPT £	Mean of difference between indicative price (FPT) and cost paid £	Median difference between FPT and cost paid £
Residential package (N=10)	975	1,042	350-2,066	962.6	12.6	- 36
Supported living package (N=13)	648.4	650	50.4- ¹ 1650	771.2	-122.8	-88
Living in parental home with support (N=5)	603.1	626	10 – 1,294	1,101.2	-498	-682

¹ £50.4 was the average weekly cost for a very independent woman, who only needed a few hours of 1-1 support to sort out her shopping and bills.

4.1 Costs of final package

The costs of most of the residential packages were actually in the range of £1,000, with a high of £2,066. However, the average was kept down by four packages which ranged from £350 - £774 per week. It is not clear why these cost so much less than the others, especially as two were for older people with healthcare needs. However, as seen in the above table, the median cost came in at only slightly more than the average, at £1,042.

In the case of the supported living packages, eleven of them came in at under £1,000. However, the average was pushed up by two particularly costly packages. The median was actually only £650, which is 62% of the median cost for a residential package.

Living in the parental home was not always just a 'cheap option'. In more than one case, people with complex and multiple needs stayed at home with their families, but inevitably had extensive support provided. In one case, this cost came to £1,294 – more than the median cost of a residential package. However, this was a person with particularly complex needs. The median cost was £626, which is 60% of the median cost of a residential package.

4.2 Comparisons with Fair Pricing Tool estimates

It was extremely difficult to get reliable data about use of the Fair Pricing Tool (FPT) in most cases. The FPT is designed to enable the purchaser to negotiate the price of a residential place. The tool provides an indicative price that would be fair for a particular individual and where the provider requests a higher fee, the reasons for higher costs should be investigated and justified. In fact, for residential cases in our study, the gap between the indicative price and the price paid was very close with only £12 more having been paid than the tool indicated.

The gap between the FPT and the actual price may be inflated by one case in which the residential package cost £430 more than the FPT. Therefore, again, it is instructive to look at the median, which in this case comes out as *minus* £36. In other words, it seems as if the FPT has mostly been successful in keeping the benchmark price of the final package down. We were told on two occasions of this actually happening, with the SSD returning to the provider with evidence that they were charging more than the fair price.

In the case of non-residential packages, we asked care managers to provide an indicative cost for that individual going into residential care, by applying the FPT. What we wanted to find out was: 'what this person would have cost if they had gone into residential care'. However, because the FPT is designed only for residential placements at present, care managers in the study did find the request difficult to deal with:

The FPT might be useful for those who are doing the financial bit of it, to see if they're getting a good deal. But a lot of the time, we as field workers don't have a choice of service. We have to look at the service and almost hang the cost, because if that's the service we need, then that's what we have to go for.

[Care manager]

Thus the resulting figures we obtained were perhaps not so reliable as the figures for residential packages. In five cases, we failed to get FPT indications from care managers, but provided an estimate through the regional project manager with the information we had about the individual. As the table above shows, the average gap between FPT and final package was £123, with a median value of - £88. In other words, 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.

Finally, we were only able to obtain a FPT cost for one person who had a support package while staying in the parental home. As with the Supported Living packages, we estimated the other four with information provided by care managers. The mean difference here was £498, with the median even higher at £682. This represents the amount per person that is being saved as a result of parental and family support. Other research (Buckner and Yeandle, 2007) has calculated the value of family carer support (for all groups of disabled and older people) to the state to be as much as £87 billion and the present findings, though limited, confirm this level of societal contribution.

4.3 Discussion of cost analysis

In general, these results support the findings from national research, which have shown that people with high support needs are costly – whatever the type of accommodation (Hallam et al., 2002). However, there is some evidence here to support a costs argument for moving away from residential care. Despite the low numbers and the vagaries of the extreme cases, it is reasonable to assume from the above calculations on actual costs, that one of these social services departments could almost have delivered one supported living package and one 'stay at home' package for the cost of one residential package. The equation looks like this:

One person in residential care = one person in supported living + one person staying at home, with support provided.

The total cost of providing residential support or supported living to any sample of people with learning disabilities is bound to depend on their actual needs. Therefore, the FPT data would be a useful way of eliminating the effect of the support needs of particular service users. There is some very limited evidence which indicates that the actual people who went into supported living, or stayed at home, would have cost more if they had gone into residential care. This finding resonates with common sense, since for

most of this group presumably a residential home would provide them with superfluous support.

No doubt, the most cost effective option for social services departments is to provide support to people to enable them to continue to live with parents. However, of course, there are many reasons why this should not be the preferred option in the longer term. Those living with older parents, in this study as elsewhere, were prone to face re-housing in crisis situations, as parents became older, ill, or indeed died. A planned transition to supported living and the development of independence skills at an earlier age, are bound to reap benefits – both in terms of the outcomes for the service user, and in terms of the eventual costs for social services.

5. Experiences of individuals, family members and care managers

Twelve interviews were carried out with individual people with learning disabilities and their carers, and these were then set alongside the care manager interview in each case, so that we could gain a three-way perspective on what had happened. This proved interesting, because it revealed in more depth the factors that really helped the process of care management, whatever the outcome (residential or non residential). With one exception, all the participants at the interview stage were young people (under the age of 30) who were moving on from the family home, or obtaining some support to access activities or short breaks, while remaining at home with parents. The following section follows the main themes arising from a qualitative analysis of the data; individuals' names are changed and details are anonymised.

Table 10: People who took part in the case studies

Group 1: those moving into residential care	Group 2: those moving into forms of supported living	Group 3: those staying in parental home
From independent flat into residential accommodation (older person)	From residential college into own home, shared with friends	Stayed in parental home, direct payments to go out on activities
From family home into residential home, then back again	From residential college into supported living house owned by college	Stayed in parental home, link family for short breaks, went to college
From residential college into residential home near the college	From residential college into supported living house	
From family home into residential home	From parental home into supported living house	
	From parental home into 'moving on' project house for one year	
	From parental home into family placement	

5,1 Satisfaction with outcomes

In all but two cases (both of which were residential placements), the family and the care manager both reported that the person with learning disabilities was happy in their new placement or activities. These judgements were made on the basis of 'increased independence', 'living with peers of her/his own age', and the activity level of the person. Actually engaging in preferred activities (which included rambling, cooking, pub visits and socialising) was

taken as an indication that the person was getting on well. Health measures (e.g. not having fits; gaining weight; not indulging in self-harm) were also used.

However, it was worrying that satisfaction of the service user was often gauged chiefly by reports from the home manager or service provider. This could be, of course, a very biased judgement. Care providers appeared to take the lead in planning and evaluating activities, with one person for instance travelling about 50 miles to a day centre, simply because it was owned by the particular care provider who ran his service. In that case, the service user appeared perfectly satisfied, but in another case, when the service user did express some dissatisfaction, the care manager attributed it to her being 'grumpy'.

People with learning disabilities themselves reported the 'good things' about their new life, typified by this satisfied customer, who had moved to a house offering short-term training in independent living:

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]

In general, we had a picture of people who were very happy and fulfilled in supported living placements. By contrast, one of the residential placements had already broken down, and another was only intended to be a temporary arrangement. The things people particularly appreciated about supported living were:

- a) new friends (especially when people were living with people of the same age as themselves)
- b) supportive staff who had good relationships with them.
- c) the opportunity to get out and do things in the community – ordinary activities, such as shopping and socialising.

5.2 Worries about moving

Sometimes there were some nagging doubts expressed by service users about where they were, and how permanent this arrangement might be. Particularly where they had previously attended residential schools or colleges, living away from home was accepted – but was seen as a temporary arrangement. People mentioned that they missed the place they had previously lived, and especially the friends they had there. They often felt cut off from their former life, like this young woman who had been to a residential college:

I had a friend called Ellie. She was funny. She made me laugh a lot. I don't know what she is doing now...I'm trying to go to those special places where people who have left (X) College can go to still. I'd like to go to those places.

[young person]

People were also, on occasion, confused about when they'd be going 'home' (to their parents) and when they'd see their parents:

Maybe my mum can come and talk to me too. She'll come. I don't know when. Where is she?

[Person with learning disabilities]

There was one case in which a residential placement had broken down, with the service user expressing their unhappiness through what was described as 'challenging behaviour'. Another young person was clearly experiencing some depression, and her care staff were concerned. This raises the important question of listening to, and monitoring, the person. In many cases, people could not predict or envisage the change that was going to take place in their lives. At least six of this group had very limited communication and understanding. Therefore, their satisfaction would only become apparent after the event, and perhaps on a gradual basis.

Where a person was staying at home, and receiving increased support, there was of course less adaptation necessary. However, those who had moved into 'non residential' options had the same kind of adjustments to make as those who had moved into residential care. From their point of view, it was the move away from the parental home which constituted the big change, not the choice of residential or non-residential care.

The message from these case studies was that care management does not stop when a person has moved. This is the time when it is most important to keep in touch, and to have a good system for really finding out whether the placement is working well. This seemed most likely to happen when the system required it – e.g. when someone had moved into a temporary situation, designed as a stepping stone to independence. Successful care management involved:

- Keeping up regular contact with the person with learning disabilities
- Talking to the person, independently of the provider
- Allowing people to change their mind, develop and move on.

5.3 Enabling the service user to have a voice

Although social services departments would adhere to the principle of advocacy and self-advocacy, it is often difficult to ensure that this occurs in practice. We asked people if they felt that the service user had been able to have a say, and if so, how this had been facilitated. Seven of the twelve people with learning disabilities had been involved in person-centred planning at some stage during the process, and this had often been initiated by the family, with varying success. Even when the person with learning disabilities could not communicate verbally, family members argued that their voice was heard through the process of pulling together opinions of familiar friends and acquaintances:

We've got a person centred plan, which was initiated because ...Jane has no communication, so it has to be much more done by other people's opinion. ... So we really invited anybody who had any contact with Jane, so we had OT's, SALT's, social workers, ex-teachers, we had people from college, people from her own village – she was a regular churchgoer. And then I even got input from her hairdresser and her dentist, they didn't actually come to the meetings, but they did tell us things. And so we had this plan, and we went down –Jane came to the meetings – it wasn't as good then, her concentration and her ability. But she did stay.

[Family member]

In one of the local authorities, person-centred planning has now been offered to a wide range of individuals through the local People First organisation, funded by the SSD. However, in other places it was interesting that several parents had had to convince social services, at some stage, that person-centred planning was worthwhile. As an outcome of person-centred planning, parents spoke of the importance of having defined goals, and of having a 'consensus' about the person's needs. It will be recalled (3.2) that a significant factor related to the outcome of care planning was the number of people consulted and involved. PCP is clearly a very potent way of pulling together a wide range of people in a person's life.

Advocacy was another way for a young person to have a voice. In one case, the introduction of an advocate had not been very successful. However, two other people had had advocates (one in an 'emergency' situation) and these people had an important role in spending time with the person, recording their wishes and representing their views. A young woman with very limited verbal communication nevertheless remembered the name of her advocate some six months later.

There were many reservations expressed about involving the person with learning disabilities too deeply. Both parents and care managers were anxious that the particular option they were looking at would not be agreed, or would not materialise, and that the person might become anxious and disappointed. One care manager explained:

I approached my manager first, because you don't want to approach a service user with an idea unless you can see it through

[Care manager]

There was also a strong theme in these interviews about 'best interests' decisions, especially for those who could not speak for themselves. However, even for those who could speak up, their interests were often decided by others. One young man, for instance, had said he did not want to go to college. However, it was deemed best for him to have activities planned into his life, so that his motivation and interests could be expanded. The new Mental Capacity Act (2007) states quite clearly that blanket assumptions of 'incapacity' should not be made. However, care plans and particularly college reviews, routinely take into account the necessity for a young person to

develop in independence. This frequently takes precedence over a person's own wishes.

It was the parents, rather than the care managers, who most often talked of practical ways to involve people in decisions, and they mentioned the following practical things:

- Taking 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 through their reactions to people and places:

Obviously over the years we know what he likes and doesn't like, and it's also become clearer that there are personalities he works better with than with others. So he will show quite clearly what he likes and doesn't like.

[Parent]

- Parents also spoke up for the right of the person to be present at meetings, whereas this was seldom specifically mentioned by care managers.

People with learning disabilities who could tell us about 'speaking up' talked about being listened to. They responded well to care managers who, they felt, had listened to them and 'not interrupted'. Some mentioned that their parents had supported them, but they also named friends and tutors at college or day centre, who had helped them to gain the confidence to say what they wanted.

5.4 Working in partnership with families

The sample of cases in this study included several in which parents had taken the lead, fought for their son or daughter's rights, and expressed very clear views about what should happen for them. In more than one case, the parents had in fact instigated the move or the change in their young person's life, and had even organised it. Those families who are the most active are in general satisfied when they achieve what they think is right for their son or daughter.

However, their relationship with social services is also key to achieving success. One single mother found that social services were not as 'proactive' as she was in making things happen for her daughter, although they did put her in touch with other parents:

It was the two social workers together who came up with some names, and left it to us as the parents to initiate contact. [parent]

Another set of 'active' parents commented that meetings had to be arranged by them – nothing appeared to happen until they organised it. While these parents did want to maintain control, to a certain extent, they wanted social services to at least provide an efficient back-up to their efforts. The most

active parents were those who had already become very well informed about service options, and had clear views of their rights. Others, however, were more isolated for various reasons, and this comment was made by someone who had recently moved to the area:

I would have expected more informed help. It doesn't make sense that social services doesn't develop a more customer-focused support facility.
[parent]

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]

Most of the social workers did in fact feel that they listened to parents' views, and always involved the family in decisions. In fact, their efforts seemed to be directed at times almost entirely at the parents, or through the parents. The running record of 'events' kept in care management files were often composed almost entirely of phone calls with parents. However, there were a few instances of social workers who judged that the parents' motives were suspect, and particular parents had gained reputations as 'difficult':

He's very difficult, he was very much for it, to be honest, it's difficult to actually say this...if it (had)worked out fine, the dad would have been the first to say...because it didn't, dad is now saying that he was never happy with the idea.
[Care manager]

In some cases such as this one, the care manager did not appear to accept that the parents' in-depth knowledge of their son could be helpful to care planning.

In at least two other cases, the needs of the parents were considered paramount in influencing the decision for the young person to move on from the family home. In one of the case studies this was because of parental illness, and in another it was because of a single parent whose working life had to take precedence over her caring role.

In just a few situations, the family appeared to be in conflict with the rights and interests of the person with learning disabilities. It was really hard to judge whether a conflict existed in the case of those who could not express their needs clearly, but there was more than one case in which this conflict had become apparent. Conflicts could take different forms:

- 1) In one case, the parents' need for the young person to move on appeared to conflict with the best interests of the young person.

- 2) In another case, parents were judged as likely to 'hold the person back' from independence, because of their own view of their son as being still a child.
- 3) Finally, a sibling had reported problems with a stepfather's handling of the person with learning disabilities. In this case, the care manager was very clear about taking immediate and direct action in favour of the rights of the person with learning disabilities.

5.5 Familiarity of care manager with the person with learning disabilities

In the new climate of individual budgets, there are questions being raised at all levels about new types of worker. In particular, the assessment and placement role of care managers is under debate. Once self-assessment is under way, will we need a team of people to assess needs and allocate resources?

Care managers in this study had of course fulfilled precisely those roles of assessment and resource allocation. However, that was often not without a degree of regret. One care manager spoke wistfully of the time when he had been able to go out with service users, on a regular basis, or even take people off on holidays. Several of those involved in the case studies had taken over the case from another colleague at the last minute and had not really had time to get to know the person with learning disabilities; they mostly felt that this was a very unsatisfactory situation. In one case, the care manager claimed to have spent some time visiting and getting to know a young woman with moderate learning disabilities. However, when we spoke with the service user, she could not even remember who the care manager was.

When we asked parents, and people with learning disabilities themselves, what they would improve about care management, they nearly always said something about getting to know the person better:

The most important thing is for them to get to know their clients, and without that, I don't see how they can move forward. [Parent]

They've got to win their trust first, haven't they? That's the first thing you've got to do. [Parent]

People with learning disabilities naturally valued the relationship they had with a good care manager, and this required contact, visits and time:

My social worker listens quite a lot. He is very talented, makes me laugh. I think he is useful, helpful, trying to help.
[Person with learning disabilities]

From the point of view of parents, care managers seldom appeared to have time to get to know the person's needs in full. Further, as we have mentioned above, they had often experienced some resistance from care managers in

engaging with information in person-centred plans. Of the twelve case studies, nine had families who were active in their support, and five of these expressed that same view – that they would have liked the care manager to get to know the person much better. One family had been bitterly disappointed by a care manager who would phone up and talk about funding, without even asking how their son was doing. However, they all realised that social services staff were very busy, and so perhaps did not have the time to do the job in the thorough way they would have liked.

As mentioned, care managers themselves tended to agree with this view. One or two of them had in fact worked with the particular service user over a number of years, and arguably did know them very well indeed. For one older woman, who lived on her own, the care manager fulfilled very much the old-fashioned ‘social work’ role, in which she kept an eye on her and knew her well, almost as a friend:

That’s a big part of it actually, if you’re working with somebody long term, which we tend to do with our people, you do get to know them... I was doing a lot of support work, you know, taking her to the post office and just making sure she was ok. [Care manager]

Is good care management just about taking the time to get to know someone? It is interesting that the care managers who were most praised, by service users and by parents, were not necessarily those who had been there a long time. Indeed, there were hints in one case that there might even be a danger in knowing the person too well, as the care manager then started to take decisions onto herself. She knew too well what the ‘best interests’ of the person were. By contrast, two of the people in the case studies had had an advocate, and this was always considered a good way for them to have their views represented. Those at residential college will be discussed further below; they also had a degree of ‘advocacy’ with staff who had got to know them well over a period of time.

It was essential for the care manager to take an interest in the person, and to know enough so that they could really follow up, find out how things are going and ‘care’ for the people they were supporting. However, the process of doing good care management involves more than that. Rather than simply going out together, the most important elements in understanding a service user seemed to be:

- Working well with the right information about a person’s needs
- Ensuring advocacy
- Respecting good person-centred plans
- Creative thinking about the possible options for that person

5.6 Good leadership and vision

When asked what had made a positive difference to the care management process, two sets of parents cited good leadership in the social services team:

It helps to have the twenty-first century vision, from the top.
[Parent]

That comment was made about a new team manager who had come to the area, and her presence was also commented on by individual care managers. They said that the funding panel decisions were now quite different, in that the needs of service users were paramount, rather than the particular sums of money.

*The managers are owning the problem, they see it as their problem.
This isn't a social worker coming along with yet another expensive idea.
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]

One request, for instance, had been turned down for a woman with learning disabilities, because the placement was deemed to be too far out of her home town, and there were too many other people in the particular residential home. The manager advised holding out for something more suitable and local, and this is in fact what happened. In that same area, some creative solutions were being found for people with learning disabilities, moving into shared homes, and managing their own lives with the assistance of a direct payment.

Leadership and vision can also be transmitted by policy, and *Valuing People* itself was mentioned by more than one family. In fact, it was a grandmother who had read *Valuing People* and suddenly realised that it applied to her own granddaughter. This is what gave her the confidence to stand up for her rights, and engage social services in discussions about community options. Instead of going to a day centre, this young woman now has one-one supporters who help her use community facilities.

5.7 Information about options available

People with learning disabilities themselves seldom have any information about what exactly is available. As we have seen in these case studies, information may even be withheld from them about the possible options, in case they do not materialise. This means that their choices are extremely limited, and often consist of 'are you happy with this place?', rather than 'which of these three places do you like best?' People who had conceived ideas about where they wanted to live had mainly gained these ideas from friends or from direct experience. In more than one area, use of a short-term break service, resulted in people with learning disabilities moving on from the family home. This was simply because they had made a contact with a possible source of support, outside the family.

Information is also extremely scarce from the point of view of families, although some had been given 'leaflets' to show them what may be available, and others had gone through series of visits in order to satisfy social services that they had 'viewed the options'. They tended to be far more influenced by knowing or hearing of other families who had had particular experiences.

- Examples of people in supported living
- Friends who had direct payments;
- People doing ordinary activities in the community
- People living independently with good support

All these were very helpful, and gave families the reassurance and guidance that they were so actively seeking:

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

The interviews with care managers revealed that information about options was in fact in short supply even amongst some social services staff. More than one care manager told us that they relied heavily on local knowledge, on sharing information amongst the team, and even on sitting in an open office where they could hear what was happening from other team members:

We're scrabbling around for places, and if I wasn't looking for Annie, I'd be looking for somebody else. We try and talk in team meetings, if there are several of us looking for placements. We have discussions – would this person go well with that person? We used to have a vacancy board, but now it's very much relying on e-mails.
[care manager]

This climate of sharing information between team members is probably not unusual. For individual budgets and self-directed services, the way in which information is generated and shared will need to be urgently addressed.

5.8 What led to residential or non-residential placements?

Referring to the three groups in Table 10, there were far more similarities between the care management process for the first two groups (those who had moved) than for the latter group. In other words, what matters is 'to move or not to move'.

From the evidence of these twelve case studies, probably the most important influence on outcome was the availability of a placement. Whether someone had to be placed in an emergency situation, or whether it was a 'planned' transition, there had to be somewhere to move to. This was just as true for placements in non-residential situations, as it was for residential homes. For instance, in one case, parents had fought for a particular 'supported living' placement, and the care manager finally agreed that their son could take it up, simply because there was a place there at the right moment. Two young people had moved into a 24-hour supported living house in a neighbouring authority, largely because the places became available at the right moment, and no alternatives appeared to exist. In another case, a residential home had opened up close to the person's parental home, and a placement there

was considered too good to miss. People who wanted more creative options, such as independent living training, still needed to queue for a place. And yet another young person had left college and moved into a residential home, simply because a preferred local option was not available at the right moment.

The agreement for someone to move from their family home was often, therefore, more an art than a science. It involved the care manager being very diligent in looking out for spare places in particular houses or homes, and in making sure the timing exactly matched the need. There were indeed instances where people had been 'hurried up' to take a place while it was available, and there seemed to be a general fear amongst parents and care managers alike, that places would disappear unless they were quick. These were comments from care managers in two different localities:

At the time we felt that it was an ideal place, coming along at just about the right time.

[Care manager]

To be perfectly honest, with a town this size it's word of mouth. There is data out there, and occasionally when you're looking for a specialist provision you do have to spend a long time on the phone.

[Care manager]

All this, of course is exactly the opposite of an empowering situation of choice. It is a system in which service users' needs are indeed secondary to the market-driven system of providers' wares; it is also a system which is so opaque that only an experienced care manager on the end of a phone can really glean the necessary information.

It was interesting, also, that this was just as true for supported living options as it was for residential placements. Indeed, it seemed from the family's point of view that there was little difference between the two. For them, the most important thing was that their son or daughter should leave home in a planned and confident state of mind, and that they would still have regular contact with them. This often meant local choices, where the person was living in close proximity to the parental home. But in other cases, parents also advocated for supported living or residential homes which happened to be near the student's former college, and where they would live with good friends they already knew.

When looking at the factors that made a difference to the decision, seven of the nine young people took up places that were available, and so had little choice at the exact time of their move. This was mostly dictated by the fact that they were due to leave college. Interestingly, no-one in any of the case studies said that cost had been an issue in influencing the placement. In one case, the Fair Pricing Tool had been used as a factor in bringing down the price quoted by the service provider. Two of the care managers indicated that they were worried about future costs, but more than one explained that it was always service users' needs which led to the final decision.

The one older person who was part of the twelve case studies was typical, perhaps, of others in the study in the over-50 age group. Previously independent, he had suffered from failing health, and so residential care was considered the best option for him. There was a strong tendency, as we have noticed, for those who were older, those with health needs, and with challenging behaviour, to be channelled into residential provision.

What, then, constitutes a better and more 'planned' transition into independent living? Luckily, the two young people who stayed at home, the one youngster who was yet to return from a residential college and was planning to move into a shared house, and the one planned move into independent living, all gave good clues as to what works better.

- Three of these four young people had families who had helped them to establish their goals and dreams, through person-centred planning. These plans had been listened to by social services staff, as well as by others involved in their lives. They stated simply and clearly what the young person's goal was, and so could guide the whole planning process.
- Two of the four were establishing lives in their local community, with support, while still living in their parents' home.
- All four of them had active care management, in that the care manager stayed in regular contact with the family and with the young person.
- In one case, a project for independent living (a 'moving on' project) had just been started, so that this provided a next step for the young person. It was an ideal option, as it did not restrict her future choices, and so she had been able to move out of her parents' home in a staged way.
- As already detailed above, the fourth person in this group was planning to move into a shared house with other friends, and the group of parents had been very proactive in planning the community life they wanted for their offspring.

Time, supportive families, creative thinking and local community seemed to be the key features for all these young people. Care managers need to respond to needs, but these responses should not just be knee-jerk reactions to crises. Ideally, they should be working with the young person and their family over a period of time, and of course this is more possible when the person chooses to stay at home with their family over a more extended period. Nevertheless, with good advance planning, transition should not be a 'sudden' event. As one parent said:

The problem is that a lot of parents of special needs young people don't know what is out there, even today.

[Parent]

The stories in the following section are composed entirely from elements of the case studies we look at in the research. In order to preserve anonymity, we have merged them into three patterns. None of them is particularly intended to provide model answers, and none of them is intended to offer a negative example. When sitting back and analysing these case studies, it is

easy enough to pick out the 'do's' and 'don'ts' of the care planning process. However, real life is not so simple, and care managers in the thick of it will have to respond as best they can to situations which are not ideal. Crises, for instance, will give rise to instant solutions, and the best planned solution can fall through at the last moment.

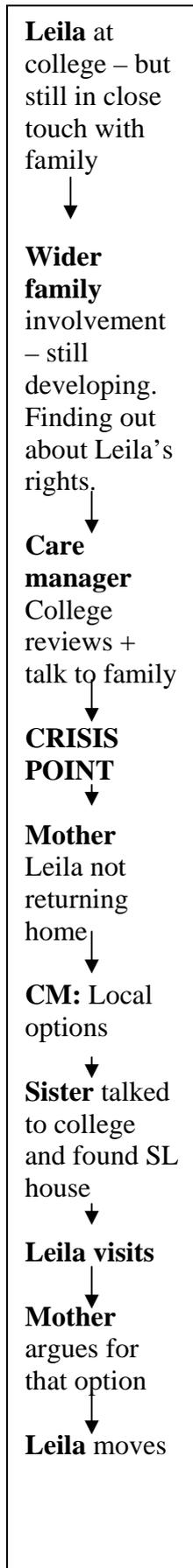
In general, however, it will be evident from these composite stories that the keys to good care planning are exactly what we have outlined above. With good forward planning, crises can be averted, and a person-centred approach will ensure that the wishes and goals of the person with learning disabilities guide the plan. Working with families and friends also makes good sense, and sometimes there will be resources in the family who will be of great help. In the end, it is necessary to have a range of options for living, although these do not have to be ready-built, empty homes! A good flow of clear information about all the options is also essential – and often missing.

The '21st century vision', as another parent said, has to be shared between the person with learning disabilities, the family and the care manager. In this respect, it is care managers who can take the lead in ensuring that person-centred planning is 'real', and that options for living are developed which can attempt to provide a range of choices for community living. Without those choices available, the quick-fix option is going to remain residential care providers.

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

5.9 Composite stories from the data



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 finds 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.

Marcus at home, likes pub and has local community connections



Leaves school, no options for FE



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



Mother and care manager start process of person-centred plan



Marcus has a plan to say what his goals are



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



Family visit and say yes



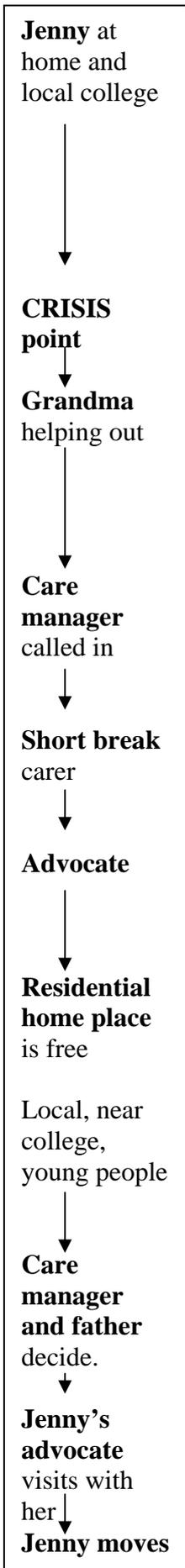
Marcus moves

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 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 tells 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.

6. Progression from further education colleges

In the total sample of 28, five were moving on from residential colleges, and four were moving on, having completed full-time courses at their local FE college. None of the four local FE students moved into residential accommodation, whereas two of the residential college students did. Additionally, two of the other residential college students moved into supported living houses which were at some distance from their parental home. It seems, then, that students at residential college may more frequently go into some type of residential provision.

Four of the five residential students were amongst the twelve case studies. Three of these had moved into 'supported living' and one into a residential home. From the interviews and the qualitative analysis, there were certain factors which these young people appeared to have in common.

6.1 Family encouragement for the move

The decision for the young person to leave the family home is often taken primarily by the parents, and relates to parental need as well as to the needs of the young person. This was no different for the two groups (the local FE college group and the residential college group). Three young people in each group had parents whose views and pressure led the process of decision-making for the young person.

However, the four case studies from residential colleges show a certain determination and ease in the family decision about moving on. The family, as one care manager said, had already taken the difficult step of allowing their son or daughter to move away to residential college.

She was very much – 'no, he can't come home'. He's got to move on into independence. And because he was already away from home, they'd already experienced that initial loss and detachment.
(Care manager)

Despite seeing them in the holidays, it seemed to be easier for these families to encourage their son or daughter to move on after college. Indeed, two of them had stated quite clearly that they were *not* in a position to have them back at home.

6.2 Young person's experience of transition to new placement

The young people themselves all appeared to accept a new placement at first. This was despite apparent difficulties which would have militated against an easy move. One young woman, for instance, was known to have difficulties in accepting change, and appeared very unmotivated about activities. However, she surprised those around her by taking to the new placement very quickly. Another young man accepted the move to a supported living placement, very much as part of his college experience. It seemed that these young people

had already experienced a move away from home. Another move was simply another step along the way for them.

However, at the point of the interview, the four young people shared the common characteristic of being slightly unsure about where they were and why they had moved there:

I don't know what made everyone decide on this. It's near home, a nice place. [young person]

I want my friend to stay, but you have to go when you're told. It's hard for Jean to go home for the weekend. Maybe my mum can come and talk to me too. She'll come, I don't know when. Where is she? [young person]

One of them, as mentioned above, was giving concern to her care staff because of signs of depression.

It may be surmised that these young people had become used to the rhythm of term-time and holiday time; they initially accepted the move as part of a 'term-time' situation, and were still waiting for the holiday to come so that they could go home.

6.3 The role of the college in transition

Residential college staff had been active, in all four cases, in preparing the young person for a move, by:

- a) Talking with the young person, often on a regular basis in careers or transition sessions.
- b) Exploring options in group situations with the young people
- c) Talking with parents
- d) Actively supporting the young person to try out new placements, for instance by going with them and staying over in a new house several miles away.

Care managers praised the college staff for the role they had taken, sometimes stating that they themselves had not had the time to get to know the young person in depth, nor to introduce them so thoroughly to their new placement:

The local college also helps people visit initially, to do the visits. But the residential colleges do more, and go and stay with them. That was an important factor.

In another case, the college had introduced the young person to a placement within their own provision; however, all were said to have provided advocacy and support. Perhaps, of course, that was even more necessary for these young people since they were at a distance from their home social services department. One care manager said:

I went to the review, and spent a good afternoon down at the college. But obviously, with it being a bit of a distance away, that limits the time you can spend there. [Care manager]

This study did not have the opportunity to talk directly with college staff; however, other recent work (Heslop et al., 2007) has shown how residential colleges generally have problems in making the link to local provision in real, concrete terms. They can help prepare the young person in general, but the actual knowledge about what is available, and where the young person could move to, rests in the hands of the local social services department. Good communication between these two agencies thus appears to be absolutely key to the process, and this appeared to have happened particularly in two cases. In the other two cases:

- The social services department worked chiefly with the parents, rather than the college, in planning future provision.
- The college worked chiefly with the parents, and the social services department possibly became rather sidelined.

6.4 Being a college graduate

The four young people who had moved on from residential college all had things to say about their former friends, and the people they missed. The severance of links with college appeared to be a big issue for them, even for those who were living quite close to their residential college.

One young woman, for instance, had very few friends. She did not appear to be communicating well with those around her, and her staff were concerned about her. She did, however, speak fondly of a friend she had known in college, and also about her former tutor:

There was a man, my tutor, Brian. At college. I'd like to see him again. [young person]

I did like ... College – they were friendly people, and I really miss it. The worst thing is that I don't like staying in. [another young person]

It was not always clear that the plans for progression from college were put into place, nor were they necessarily known about. One young person in supported living was doing a college evening class, but did not have a plan for moving into work (despite this being on his records from college). The care staff did not appear to be aware of his vocational preferences. Another young person had parents who had been very active in arranging his continued support. They were very aware of the things he had in college, which needed to be continued, such as Speech and Language therapy. In this case, the parents provided the very strong link between college and future living. In other cases, the parents had moved back a step to take a lesser role.

Communication and ongoing links seemed to be key themes. For young people to experience a successful and meaningful transition into independence, supported living, or residential accommodation, they need a sense of continuity with their previous friends, support staff and with their own planning for the future. The 'overlap' period does exist, in which college staff will meet future care staff, and information presumably is shared. However, from the point of view of these young people, the connections needed to be stronger and longer. Reunion and friendship groups; continued college visits; continued contact through email, webcam or phone; social gatherings which involved college and home carers; all these strategies could help the young person feel that they are moving on in a planned and connected way into a future which is meaningful for them.

7. Conclusions and recommendations

There are many reasons for moving on from a dependence on residential placements. The eventual outcomes for service users have to be top of the list, but this study showed some, albeit limited, evidence that supported living options were also more cost effective. Although small, this study of care planning for people with learning disabilities has broadly reflected the national picture; those with higher levels of need tend to be placed in residential accommodation. Additionally, people over the age of 50 seemed to have very few other options.

What do we have to do, in order to shift the balance towards a range of supported living options for people with learning disabilities? Simons (2000) put it like this:

Supported living does not represent a single model. It involves using a range of tools and techniques to try and ensure that the housing and support arrangements fit the needs and wishes of individuals involved (hence a strong emphasis on person-centred planning).

[Simons, 2000: 9]

Now, some seven years later, the current study is still indicating that a planned transition, in which person-centred planning is in place (and is taken into account in the care plan) is a good way to ensure people have a chance to think about what they really want. Crisis situations tended to result in quick-fix placements in the nearest available residential home.

Perhaps even more striking in this study was the lack of information and choices available, both to people with learning disabilities and to social services departments. Unless families were really 'proactive', they could easily be told that they had to take up the first available placement, whether this was a residential or a supported living placement. Care managers, for their part, seemed to rely heavily on covert, local knowledge about availability. Therefore, the development of alternatives to residential placements still relies on a) real models of what works for individuals; b) information about actual places and options available for people. All too often, there appears to be a secrecy and reluctance to share information, in case the placement is snatched up by someone else. In this context, a regional database of providers has been started (since March 2007), and so this now needs to be better publicised and used, in order to flag up vacancies.

People with learning disabilities themselves were seldom involved in decisions about their future in a concrete, meaningful way. Even when they had taken part in planning and had expressed their wishes in general, there was very much a 'best interests' culture about deciding where to move. Once a placement had been found, the person with learning disabilities generally went to have a look. However, it was very hard for them to have any comparison with other options, nor (in some cases) to know what 'moving' would involve for them. Therefore, another key recommendation must be about involvement in decision-making. Information about living options needs

to be made accessible to people with learning disabilities themselves, and we need to start accepting the risk that they might be 'disappointed'. Those who had advocates in this study were more likely to become involved in actually making choices.

Parents and family members were far more likely to be consulted about future living options, than their son or daughter with learning disabilities. In most cases, parents in this study provided excellent advocacy for their family member, and promoted person-centred planning as well as an independent lifestyle. Parents naturally want the best for their son or daughter, and these parents had extensive, detailed knowledge about what would work best. In order to ensure that more parents can really 'lead the planning', then better information needs to be targeted at parents. Successful care managers were good at empowering parents, and not impeding them, and this was a sure way of promoting more 'non-residential' options. This study found overall that parents were *not* promoting residential accommodation for their son or daughter.

Care managers in this study had not generally worked out an individual budget for their clients. It would clearly be helpful to get a more accurate picture of the individual budget for each client. Care managers were, on the whole, more diffident in talking about financial matters than about other aspects of the cases. Sometimes they themselves appeared unclear about the financial agreements, and sometimes they felt unsure about detailing them to others. It would seem that more training and sharing of good practice in financial planning would be very valuable.

Finally, this study did not include any cases in which a direct payment had been granted for independent living. As mentioned above, there were two cases in which direct payments were used as a supplement for supporting day activities. However, it would be good to see the concept of 'supported living' developing into a range of choices for individuals; in many cases in this study, supported living houses were operating under the same constraints as residential provision (e.g. availability of placements in short supply; residents had no choice of who to live with; staff employed by the service provider, not the resident; group living and rotas dominated the lifestyle). This finding is in line with work by Fyson and Ward (2007). What we urgently need is more examples of living options which are qualitatively different from a group-living situation. Care managers could then have the confidence and ability to advise individuals about alternative routes to independence.

In summary, the recommendations for social services departments are:

- **Ensure good leadership and vision 'from the top', with management that encourages open discussion of individual budget and direct payments options, together with creative ways of thinking about support packages.**
- **Ensure a person-centred plan, and take it into account in care planning**

- **Routinely ask families and individuals about the existence of a person-centred plan, and for their permission to use it in care planning.**
- **Work in partnership with providers to offer a wider range of options (including supported living, shared ownership, renting, group living), and to make information on this more widely and openly available.**
- **Make better use of the regional database of providers, in order to flag up vacancies.**
- **Make accessible information about housing options available to people with learning disabilities themselves, and encourage them to pursue these options – to visit and discover for themselves what they would like.**
- **Work with families, ensuring they also have good information, to release the potential for good support and advocacy.**
- **Ensure independent advocacy for people with learning disabilities who are moving on.**
- **Judge satisfaction with outcomes by continued work alongside the person with learning disabilities, if necessary through an advocate.**
- **Use tools which are available for working out individual budgets for service users.**
- **Create more training and support opportunities for care managers in financial planning and use of the fair pricing tool.**
- **Use direct payments and IB flexibly, in order to develop a range of different lifestyles for people with learning disabilities.**

1. Setting up the research

This study benefited from an advisory group, which consisted of funder representatives, a direct payments financial advisor, a parent and two service users with learning disabilities. The group met twice, once towards the beginning of the project, and once at a midway point. They advised on consent procedures, the content of the record search protocol, the headings for analysis of the case studies, and the content of the interviews with service users and carers.

This was a mixed methodology study, which aimed to capture processes and critical factors through an examination of individual cases. In order to gain maximum insight, two main methods for data collection were used – a) record searches; b) interviews.

2. Identifying and approaching participants

Four social services departments (SSDs) who had agreed to take part in this study were asked (through nominated key contacts) to identify ten people with learning disabilities who had reached an ‘outcome’ from their care planning between September 2006 and February 2007. They were then asked to send out information and consent sheets to those service users, and to let the project team know of at least ten anonymous individuals who had consented to take part. The intention was to select randomly an equal number of ‘residential’ and ‘non-residential’ outcomes for each SSD.

The research protocol, with associated consent procedures, was approved by an independent ethics committee at the University of Bristol. Particular attention was given to providing accessible information about the project to all parties, but in particular to the people with learning disabilities. All the service users concerned in the study were passed easy information sheets about the project, and (with support of family, or carers) they gave their consent for their records to be examined. At the same time, they were asked if they would like to meet one of the researchers for an interview.

In the event, the flow of ‘cases’ with full consent was extremely slow, and so the time frame was extended to September 2007. The final number of cases was 28, instead of the target number of 40 overall, and the research team had to be satisfied with an uneven number of ‘residential’ and ‘non-residential’ outcomes (10:18).

3. Record searches and care manager interviews

Each record search was accompanied by an interview with the care manager concerned, which served both to set the scene and clarify matters, but also to explore the views and concerns of the care manager about the process of care planning. On factual matters, for instance, we asked them for a thumbnail sketch of the person and outcome; for information about how long

they had worked with the service user, and for facts about the referral, the other options explored, and the costs. On a more exploratory note, we asked them for their opinion on what had been the 'deciding factor' in the outcome, and what had worked well about care planning for each service user. Care managers were all very helpful in providing interviews, telling us about what happened from their point of view, and expounding on their views. Interviews were all recorded (apart from one in which the care manager was unwilling to use the recorder), and transcribed. The transcripts were used a) to clarify any matters which were unclear from the record search; b) to set beside the user/carer interviews for a thematic analysis.

Protocols for the record searches were developed by discussion with the core research team and funders; they were then revised in consultation with the advisory group, and piloted in the first few cases, before the final revision. There was some variety in the level of detail and clarity in the various files we searched; however, it mostly proved possible to glean the information we needed from the care managers, if it was not obtained from the file. We took care to re-assure care managers that the exercise was *not* about checking up on their record keeping.

The main problem in obtaining information related to costs. In some SSDs, financial information was kept quite separately from the main client record, and the care managers did not have ready access to it. In others, the actual costs were unclear, and in many cases, there was no FPT information. Care managers were often reluctant to be explicit about costs, and the research team had to take pains to double-check information about costs.

4. Service user and carer interviews

We were able to follow up 12 of the cases, in which service users and/or their carers had offered to talk to us. This was particularly useful in order to judge the value of the outcome, but also in order to discuss the process of care management from the point of view of service users and carers. We followed a topic guide, and (in the case of service users) a pictorial form which could be drawn or written on during the interview. The topics guide was created in discussion with the advisory group, and followed the main factors which we felt at that point might be critical for care planning and outcome. These interviews were also audio-recorded, and transcribed.

5. Analysis

Information on the record search protocols was entered into an SPSS spreadsheet, and descriptive statistics are reported.

Transcribed audio data from the interviews were analysed qualitatively, according to the themes which emerged. Where a service user interview and /or a carer interview matched a care manager interview, a 3-column table was created to compare each key factor from the 3 different points of view, and to determine any conflicts or agreements between care managers and service users/ carers.

6. Limitations of the study

Due to low numbers in the study, it was not possible to carry out formal factor analysis. Additionally, some of the factors we searched did not fall neatly into the intended categories. For instance, it was possible for someone to have very few people involved in their care planning, but to have a larger number of people involved 'behind the scenes'. That may well have been true, for instance, with those in residential specialist colleges, where we did not obtain information directly from the colleges themselves. The results presented in this report are accurate, and the trends we discuss resonate also with other national work. However, with larger numbers, we may have been able to report findings with more confidence.

It ought to be pointed out that this study pursued the very ethical path of asking each service user before looking at their file. Although it was the correct approach ethically, this procedure no doubt slowed down and complicated the process of consent and access to the files. Many people with learning disabilities do not know that files are kept about them in social services departments, and so a request to look at the file will have either seemed difficult to understand; or it would have raised questions about the files themselves.

Further research in this area would be very valuable, especially with the introduction of individual budgets, and with the expansion of supported living opportunities. It would be particularly interesting to follow up and compare cases in which:

- a) a direct payment had been granted
- b) an individual budget had been worked out
- c) a person had been placed in a supported living provision.

Care manager/ service user/ carer interviews

Topic guide

	Care manager	Carer	Service user
Satisfaction with outcome	What was the outcome? And How happy is the person with learning disabilities?	What were the outcomes like for X? Do you think this is what s/he wanted? (make this more explicit – ‘are they happy?’)	What’s it like for you now? What are the best/ worst things?
Starting things off	Who started things off?	Who contacted social services – how did the care management process start off?	Can you remember how you got in touch with social services?
Process: listening to the person with learning disabilities	How did you listen to the person with learning disabilities (and follow-on questions)?	Do you feel that X had a voice in saying what he/she wanted during this process?	Did you have a chance to say what was good/bad about your life – and what you wanted to do?
Process: listening to the parents	How did you listen to the family’s views?	As a parent, what was your own role in sorting things out?	Did other people help you to say what you wanted – if so, who were they?
Choices	Other things that were considered	Did X have a choice, and if so, how were the choices looked at?	Did the social worker give you choices? If so, did you get to visit places and see them?
What led to the decision?	What things led to the decision for the person?	What do you think were the key factors in making the decision for X’s future?	What do you think made everyone decide that this was the right place (thing) for you?
What worked best for you?	Thinking about how this care planning has happened, do you feel it’s been a successful process? And if so, what factors do <u>you</u> feel have helped (or hindered) it?	What worked best for you?	What would make it better for you? What was good and what was bad about sorting things out with your social worker?

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