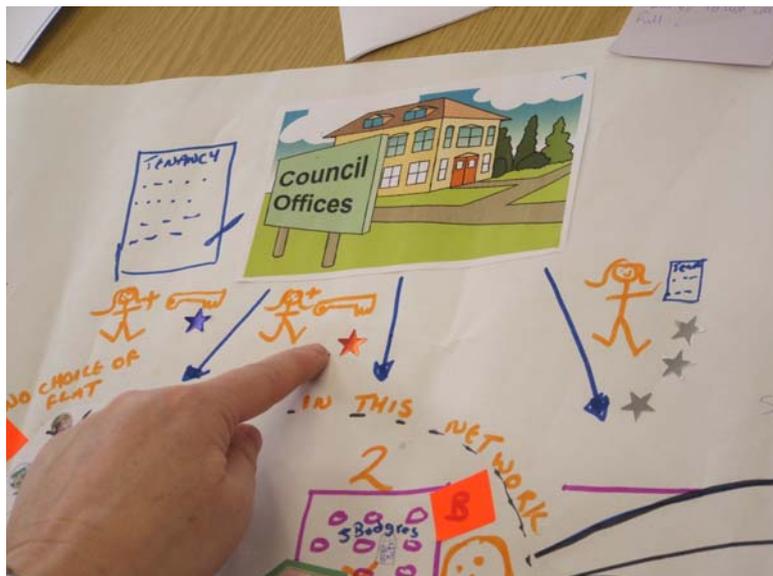


## **‘Listen to what I want’ The potential impact of the Mental Capacity Act (2005) on major life decisions by people with learning disabilities**

**Report for the Social Care Institute for Excellence  
July 2008**



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The biggest thanks must go to all the people with learning disabilities, and their supporters, who told us their stories about big changes in their lives. Their insights into their own lives are at the centre of this report, and we hope we have done them justice.

## Executive Summary

- 'Listen to what I want' (Jan-May 2008) was a short study of major decisions in the lives of 20 people with learning disabilities, from their point of view. The overall purpose was to learn more about the potential impact of the Mental Capacity Act (MCA) with people with learning disabilities.
- Participants in this study had been routinely considered unable to make their own decisions. In particular, unwise decision-making was frequently confused with incapacity.
- Most of the decisions in our study took place before full implementation of the MCA, but they give indications of good and bad practice for the MCA.
- Social services departments and care managers regularly make decisions with family carers, on behalf of people with learning disabilities. In a regional South West study, 21 out of 28 people who arguably did have capacity were only involved in decisions about moving at the end of the decision making process.
- People gave us examples of both good and bad practice in supporting their decisions. From these examples, we constructed models and a checklist of good practice, which were tested out with professionals and people with learning disabilities.
- The MCA needs to tackle ingrained assumptions about incapacity, and to ensure that people with learning disabilities get good, explicit support for their own decision-making, before they are assessed as incapable.
- People with learning disabilities need good, clear information from people they can trust.
- People need alternative options that are 'real' and the opportunity for direct experience of the options.
- People with learning disabilities often need advocacy in order to make their own voice heard. Advocacy should be independent, and should include peer support.
- We need to take into account the role of emotions, family and cultural values, timing, place and confidence. All of these factors can affect decision-making.
- It is important that the MCA does not promote a 'tick box' mentality. Much of what is in this report reflects existing good supportive practice, for instance in giving people easy information.
- Training for support staff and 'decision makers' should focus on practical aspects of support, and also record keeping.
- The personalisation agenda, person-centred planning and peer support all feed into good practice in ensuring that decisions are supported well and carried through into practice.

This report includes three tools for practice that were developed and tested with people with learning disabilities, their supporters and managers.

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## 1. Introduction and background

The Mental Capacity Act 2005 (MCA) is designed to support decision making by vulnerable people, to provide workable functional assessments of capacity and to ensure that those who are deemed incapable of a particular decision at a particular time will have proper advocacy, so that a 'best interests' decision can be taken on their behalf.

In the case of people with learning disabilities, however, decisions have routinely been taken by other people, in particular by family members, carers, care managers and other professionals (Robertson et al., 2001). There is often a blanket assumption of incapacity, which is deemed to be central to the definition of 'learning disability' (Simpson, 1999; Williams and Holman, 2006). In their personal lives, people with learning disabilities are often under the control of others (Rapley, 2004; Antaki et al., 2007; Finlay et al., 2008). Although government policy promotes 'personalisation' (DH, 2008), there is some urgency for some basic knowledge about how to advance practice in the field of Learning Disability support, to ensure person-centred approaches (Felce et al., 2001; Mansell and Beadle-Brown, 2004; Hatton et al., 2006).

The MCA aims to clarify and offer legal redress to judgements of capacity and incapacity, as they affect all people who may be incapacitated at particular points in time. The Act is underpinned by five statutory principles:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The Act is supported by a Code of Practice (DCA, 2007) which reinforces the principles to do with autonomy and support in the Act. For instance, each decision, for each person, is seen as a separate situation. In other words, people should not be thought of as generally 'incapable' of making decisions. People should also have as much support as they need to make their own decision, and should be given clear information that they can understand. In the case where a person does need someone else to speak for them, the MCA enshrines the right of a 3<sup>rd</sup> party to make 'best interest' decisions. Much, therefore, hangs on providing sensitive functional tests of capacity. Assessments should be informed by a 'functional approach' that takes into account a person's ability to understand, appreciate and manipulate information rationally, and to communicate their preferred choice.

## 2. Purpose and objectives of this study

In the light of those concerns, the current study set out to describe the potential impact of the MCA on major life decisions made by people with learning disabilities. The objectives were:

- a) To map the major life decisions which individuals with learning disabilities are making, have made or are about to make (N= 20).
- b) To create a baseline of how 'decision-making' capacity was generally judged by social services during care management, prior to the MCA.
- c) To provide a comparative measure from the point of view of people with learning disabilities by:
  1. identifying good practice tools for supporting major life decisions
  2. identifying good practice tools for carrying out 'functional assessments of capacity'

This report will follow the three main objectives of the study. After an outline of the methodology used in Section 3, we give three composite stories to represent the 20 maps of decisions we gathered from the workshops. These were all stories that had started (and in nearly every case, were completed) before the implementation of the MCA. The following will help to indicate the level and types of decisions which we are discussing, which included the following range:

- Important (but not irreversible) decisions about jobs
- Major decisions about relationships, including marriage
- Direct Payments decisions: whether to take up Direct Payments, and choosing who to employ as your personal assistant
- Financial decisions about budgeting
- Decisions about moving house, and particularly moving out of the parental home.
- Decisions about starting a family

Based on the data from the workshops, Section 4 then looks at the 'fit' between these and the MCA. We will consider the evidence under each of the statutory principles of the Act, paying particular attention to the issues raised in the Code of Practice. Section 5 of this report draws on Williams et al. (2007) to consider how care managers' actions prior to the MCA match up to the MCA principles when they were assessing and organising care packages for people with learning disabilities. Section 6 outlines and describes positive principles of supporting decisions and assessing capacity, based on themes arising from the data from the point of view of people with learning disabilities. These are in effect the main recommendations arising from this work. Further applications for practice were discussed at our action workshop, and the outcomes are included in Section 7 of this report.

### **3. Outline of methodology**

#### **3.1 Inclusive model of research**

This was a short study, carried out over seven months, which aimed to gather data from people with learning disabilities, about sensitive areas of their lives, in a maximally supportive fashion. The MCA aims to accord maximum opportunities for involvement in decision making to people who are ordinarily assumed to be incompetent. Therefore it was important that the methodology for the study mirrored those themes in the Act. Inclusive research (Walmsley and Johnson, 2003) comprises many models of including people with learning disabilities as active researchers. In this case, a person with learning disabilities, Lisa Ponting, was recruited to the study, who had experience of a previous project, 'Skills for Support' (Williams et al, 2007a) which examined the skills of personal assistants in supporting everyday choices. She was supported by a personal assistant, and by the lead researcher who had recently worked with her.

Lisa's role was envisaged primarily as supporting and helping to run the workshop days.

- She played a vital role in planning for the project as a whole, and in advising on the format of the workshops. For instance, she had very clear ideas about what it meant to be 'in control' of her life; she told us about how important smaller decisions are, as well as 'big' decisions, and this led us to have a warm-up activity in the workshops around that theme.
- Lisa also advised on accessibility of all the project materials.
- She led two of the workshops, and the final action workshop, as chairperson.
- With support, she facilitated two of the individual sessions, where participants told their stories about decisions.

In any future or more in-depth study in this area, we would recommend that people with learning disabilities take on central and active research roles, as their lived experience of decision-making helps the research to become more sensitive to the needs of all the participants.

#### **3.2 Advisory group**

In addition to the inclusive research team, an advisory group was formed, which met twice during the course of the study, and attended the final action workshop. The advisory group included another person with learning disabilities, as well as the whole project team (four researchers), a volunteer law student, and an advocate.

- The first advisory group was held at the point of submitting all the materials and procedures for ethical approval (University ethics committee for the School of Applied Community and Health Studies).

Therefore one of the important tasks for the group was to advise on the accessibility of information sheets for participants in the project. It was also a forum to pilot the workshop approach, and to develop some of the methods for visual recording of decision maps.

- The second advisory group was an opportunity to overview the results of the three workshop groups, and to plan the final action workshop.

### 3.3 Ethical matters

The protocol and consent procedures for the study were approved by the ethical committee for the School of Applied Community and Health studies at the University of Bristol. Potential participants were approached by three different support or advocacy groups, who had agreed to take part in the project. Accessible information sheets were sent to group co-ordinators, to pass on to members, who then volunteered to come to workshop days (see below). At the beginning of each day, we repeated the information about the purpose of the study, and about confidentiality, so that participants could decide whether or not to take part at that point. All the participants in this study were able to consent for themselves.

### 3.4 Data collection and analysis

**Objective A: Three workshop days** were held, at which people with learning disabilities came together to talk about decision-making and to learn about the MCA. Table 1 shows the numbers in the three groups. Parents with learning disabilities were deliberately targeted in Group 2, since we wished to look at a wide range of major life decisions, including those made by and for parents with learning disabilities, and how these might or might not be affected by the MCA.

**Table 1**  
**Workshop days**

	<b>Host organisations</b>	<b>Number of people</b>
<b>Group 1</b>	People First group	<b>7</b>
<b>Group 2</b>	Support group for parents with learning disabilities	<b>5</b>
<b>Group 3</b>	People First group	<b>7</b>
<b>Total</b>		<b>19</b>

People volunteered to take part in these workshop days on the grounds that they had had a recent, major change in their lives. Table 2 shows the major life changes that were described by the participants.

**Table 2**  
**Major life changes**

<b>Group 1</b>	<b>1</b>	Leaving college and getting a job
	<b>2</b>	Moving house
	<b>3</b>	Getting engaged to be married
	<b>4</b>	Getting engaged to be married
	<b>5</b>	Moving out of parents' home
	<b>6</b>	Moving house
	<b>7</b>	Moving out of own flat, to live with family members
<b>Group 2</b>	<b>1</b>	Having children with 'inappropriate men'
	<b>2</b>	Getting together, having a family and family planning
	<b>3</b>	Getting together, having a family and family planning
	<b>4</b>	Deciding on appropriate care for their children
	<b>5</b>	Deciding on appropriate care for their children
<b>Group 3</b>	<b>1</b>	Moving out of parents' home
	<b>2</b>	Budgeting own money for major items
	<b>3</b>	Deciding who to live with
	<b>4</b>	Becoming a direct payments employer
	<b>5</b>	Giving up a job and deciding whether to get a new one
	<b>6</b>	Moving house
	<b>7</b>	Moving house

Each day included:

- a) information about the project and about the MCA
- b) personal stories, with visual mapping (maps were photographed)
- c) group discussion based on questions relating to supports provided and decision-making.

a) The data we collected during the three workshop days were partly from group discussions, at the beginning and end of the days. To that extent, the groups operated very much like focus groups, and the data were audio-recorded. The opening of the workshop days included information and input about the MCA, for groups and supporters. This was led by Marcus Jepson, who is a PhD student conducting research about the MCA, and he used a published photo story ('Tony's story') to illustrate how the MCA could work in assessing capacity. These aspects of the workshop days were very important and helped to set the context for the individual stories.

b) Participants then split into separate 1-1 pairs with a facilitator, to tell the story of a big change they had made in their own life. Participants were all assured of anonymity, although some subsequently agreed to show their stories to others at the action workshop. We were particularly interested to

see where people had been involved in decisions, where they felt in control of the decision, and where they got good information and support. We were also of course interested in where these things had not happened, or where there was bad practice. These stories were all recorded as 'visual decision maps' and the data were also audio recorded where possible (three people chose not to use the audio recorder).

The visual maps were created by discussing each story in as open and free a way as possible, and then recording the main points in that story, with each participant, on flipchart sheets. In order to make the maps accessible, we used a combination of free drawing and picture symbols, which had been pre-printed. Following the creation of each map, we then went back over the content with the person with learning disabilities, asking them when they felt most 'in control' of their decisions. They used stick-on stars to indicate greatest levels of control, and stick-on squares to indicate where they felt blocked. As far as possible, these 1-1 sessions were also audio recorded, although three people preferred not to use the audio recorder. However, in those cases, full notes were obtained of their stories.

The workshop days took place in the early part of 2008, and so were subsequent to the implementation of the MCA in October 2007. However, none of the people who came to the workshops had had a functional capacity assessment during any of the decision-making they described to us. One of the final decisions had been made after October 2007, and one was still in progress. However, others all pre-dated the implementation of the MCA. What we were examining, then, largely were their stories about decision-making and the extent to which they would have fitted with the MCA requirements. How should the MCA actually impact on the experiences of these twenty people with learning disabilities?

c) At the end of each workshop day, the participants got back together to discuss the main points arising from their stories, and the themes that were important for them. We asked each group at the end to finish with their 'main message' for policy makers, and we have included those at the conclusion of our report.

The data collection methods we used worked extremely well in eliciting open stories, but also in helping participants to focus on aspects of decision making that were important to them. In devising these methods, we were aware that many of the things we were doing would also be important ways of actually supporting people in their decision-making – creating safe environments, sharing and supportive discussion, individual and confidential talk, visual methods of recording, peer support. One of the participants pointed this out at the end of a workshop, and we were pleased to have the following evaluation:

*This workshop is how we can change people's minds. And it's how they treat people with learning difficulties. As a group, we have been treated equally and we are now more in control of what other people are saying.*

## **Data analysis for Objective A**

The analysis of data was qualitative, and aimed to capture some of the underlying important issues in all the stories people told us. The transcripts of the audio data and the outlines of the visual stories were analysed first to extract the main themes that arose. We then looked at the data through the lens of the five main statutory principles of the MCA, to check how these principles were (or were not) reflected in the data. This was done by checking back through the transcripts. Since we had a large research team, we were also able to check the final analysis with each other.

## **Objective B: Baseline measure of capacity assessment**

The original plan had been to conduct record searches, in order to find out what stance social services care managers had taken towards assessment of capacity and towards supporting the decision of the focus person. This was not possible, partly because of the very wide range and breadth of decisions and life stories which participants told us. This situation was discussed with SCIE.

In order to gain some measure of how capacity was assessed prior to the MCA, this report will therefore draw on some recent work about commissioning carried out for the South West Regional Centre for Excellence (LIFT), in which four local authorities in the South West took part. Twenty-eight record searches and care manager interviews were carried out, relating to people with learning disabilities who had major life changes and care packages allocated during 2006-7. Part of the goal of that study was to describe the factors that constituted good practice in care management, including the degree to which the person with learning disabilities was supported to make their own decision. The full report is also available (Williams et al., 2007).

## **Objective C: Good practice tools**

The findings from the three workshop days contributed to the identification of 'good practice' tools for supporting decision making in people with learning disabilities. Additionally, a final action workshop was held, to which both the original participants and seven professional service managers, social workers or advocacy coordinators were invited. The purpose of the action workshop was to discuss the full implications of the MCA, in the light of the decision maps we had drawn with individual participants. The goal was to produce and validate practical tools, in the light of the concerns and experience discussed by people with learning disabilities themselves.

There were 23 participants at our final action workshop, which brought together people with learning disabilities (especially those who had originally participated in the mapping workshops) and professionals who had an interest in supporting decisions under the MCA. This was a useful mix of participants to discuss these topics; instead of developing materials and approaches about the MCA in isolation, we were able to ensure that the points made and

the tools discussed were in accordance with the ideas and wishes of the people with learning disabilities themselves.

**Table 3**  
**Participants at final action workshop**

People with learning disabilities	Group 1	3
	Group 2	2
	Group 3	3
	Additional self-advocate	1
Professionals	Self-advocacy coordinators	2
	MENCAP staff	1
	Senior service manager	1
	Middle service managers	2
	Care manager	2
Facilitators	Norah Fry staff	4
	Co-researcher with learning disabilities	1
	Steering group member	1
<b>Total</b>		<b>23</b>

The action workshop started with information and an overview, both of the MCA and of the results of the project. One of the original participants showed and explained her decision map, and some discussion was held around the issues raised about: choices; the implications of the MCA; the nature of decisions; the perspectives of people with learning disabilities about their own decisions. The tools for good practice in supporting decisions and assessing capacity, which arose from this study, were presented to the workshop.

In the second part of the workshop, groups were formed to discuss specially prepared vignettes, which illustrated some key dilemmas and issues about the implementation of the MCA with people with learning disabilities. These were discussed with reference to the two 'models' of good practice, and during the feedback session, points were noted where amendments were suggested. Additionally, two of the groups and the final feedback session were audio-recorded, and transcribed to extract key points.

Tools for functional assessments of capacity were examined and considered by practitioners and by people with learning disabilities, through the use of vignettes about decision-making, which were discussed in small groups. As a result of the action workshop, the tools were slightly adapted, and are given in Section 7, along with a brief description of other outcomes from this final stage. The agenda, the presentation and vignettes are given in the Appendix.



**Kath Sawyer, workshop participant, showing her decision-making map at final action workshop**

## 4. How would the decisions made by people with learning disabilities in this study fit with the principles of the MCA?

This section now turns to the findings from the decision-making workshops we held. We have grouped these findings under the five statutory principles of the MCA, so that they can provide a 'baseline' of practice in the period just before implementation of the MCA.

### 4.1 First statutory principle of the MCA

- **A person must be assumed to have capacity unless it is established that they lack capacity.**

Eleven people who came to our workshops told us about successful changes they had made in their lives, all with support from others around them. One person had received support from People First, and had chosen to take up direct payments and had appointed her own support worker. Several people spoke about person-centred planning in helping them with their decisions:

*The last couple of years they've done person-centred planning and I got more involved*

Two people had decided to become engaged, and many people had moved to new houses or flats, often associated with a move from the parental home.

Despite this evident ability to be involved in decisions about their own lives, the issue of capacity proved to be a very sensitive and difficult one in their stories. As we have said, none of these twenty people had had any formal assessment of capacity. However, they told us of many situations where their incapacity had been assumed, and where they had had to 'prove their capacity' in order to decide something for themselves.

Every one of the twenty people who came to workshop days had been in situations where other people had made decisions for them, and where they had not been given the right to determine their own future. There were frequent occasions on which people had been assumed to be incapable because they were seen as 'people with learning disabilities', a situation known as a 'status' approach to assessing capacity (Wong et al., 1999), which would be in direct contradiction to the MCA. One person who had been in a college course, for instance, told us that she felt that the tutors made decisions for all the students with learning disabilities:

*When we went on a residential, the tutors used to make a decision for us. They used to make a list of activities, and what we were doing. Say that we were going shopping, so most people hate shopping – so the tutors used to say 'you are going shopping whether you like it or not'. We used to feel that they were mainly doing it to us, because we were learning difficulties, and we couldn't make that decision. We may have learning difficulties, but we can still make our own decisions.*

The same kind of status approach to incapacity had been assumed by staff in job centres:

*We went to the job centre, but we didn't have much luck there. The person who does work with people with learning difficulties wasn't there. So then my tutor had to explain to the person in the job centre what a 'learning difficulty' was. And this person goes 'we can't work with people with learning difficulties. We haven't got much understanding'.*

Even where people had been part of formal review processes, they frequently had the impression that they did not have a voice. In one case, for instance, a man in his 50s remembered how social workers and other people involved in his life would meet and decide what was going to happen, while he himself was not asked:

*We used to have these meetings where they'd talk about what had happened in the past and what was going to happen in the future but... it was all about what they want, they were saying what was going to happen, this and that, and I used to sit there and think, 'well you haven't said anything to me!'*

In another case, a woman whose father had just died was assumed to be incapable of taking part in the decisions about her father's burial. Although people were telling us stories about their lives, none of these incidents belonged to the distant past; in fact some were very recent. There were several points to note:

- People with learning disabilities were often shielded from decisions, or considered incapable of organizing their own lives.
- These judgments were made routinely, and were not accompanied by any systematic assessment of capacity.
- The judgment of incapacity was naturalized in people's lives, so that it was not noticed. It was part of what it means to people to be treated like 'someone with a learning disability'.

One of the problems about assessing capacity was that it could be confused with a judgment about skills. When a person with learning disabilities wanted to move, they could be held back by staff and family considering they were 'not ready' for independence. This was what happened to one man, whose housing association staff told him he could not move on:

*But where I've been saying it and they've been saying, 'no you're not moving out'. The boss that owns the house, she's been saying 'you're not moving out because you haven't learnt loads of stuff, like how to budget your money and all that stuff.' I will get support with that if I did move out.*

Like many of the other stories we heard, this was a familiar scenario. It was not just that a person with learning disabilities was considered 'incapable' of decisions; their decisions were not respected, because they were considered

not to have the skills to back up those decisions. Skills and decision-making capacity were very closely entwined in people's lives, and nowhere more so than in matters relating to parenthood. All the parents we spoke with had been considered 'less than adequate' parents, and all had faced situations where the decision about keeping a child was taken out of their hands. This was because of the supremacy of Child Protection laws, which will foreground the rights of the child. However, in the light of these situations, other decisions were taken from some of the participants. For instance, one woman told us about going into hospital to have a baby, who was immediately taken from her, without any discussion. She was apparently unaware that this was going to happen, and was not allowed to discuss that decision at all.

From the stories we heard, then, the first principle of the MCA has regularly been flouted in the recent past. People with learning disabilities were often assumed to 'lack capacity', and their ability to make a decision was regularly confused with a negative assessment of their practical skills (e.g. baby-management skills; financial skills). From the evidence of this project, prior to the implementation of the MCA, we have seen that the label of 'learning disability' was often used as a blanket way of denying people the right to autonomy.

## 4.2 Second statutory principle of the MCA

- **A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.**

Decision-making in general is done in social situations (Harris, 2003; Jenkinson, 1993). This second principle of the MCA is largely about the kinds of support for decision-making which can be given by other people. The MCA gives examples of what it means by 'practicable steps' for help, which include:

- accessible information
- involving trusted people
- paying attention to where and when the decision is going to be made.

Several of our participants felt that they had been involved and felt 'in control' through having supportive discussions with other people, as this person said:

*They didn't have anything to do with the decision. I made it myself, with various support that I've got around me.*

Family carers were also mentioned by many participants, and their involvement had worked in different ways. Family carers had supported decisions to get engaged, to move house, and to get jobs. One of our major observations was about the length of time and many different stages in a major life decision. One very common pattern seemed to be that family members wanted to have information first, before they discussed it with the person with learning disabilities. It was often assumed that family carers had

to be 'happy' with something before going to the next stage. Therefore, the 'practicable steps' mainly seemed to consist of providing information to families, rather than directly to the person with learning disabilities themselves:

*Jane and my mum talked about the office job. In the end, Jane decided that I should be involved, and say whether I wanted the job. And people were making decisions for me.*

One of the main 'practicable steps' we heard about, in supporting decisions, was the arrangement for someone to have direct experience of a particular option.

- One person had a work placement, to find out if he liked working with animals; he then decided that he did not.
- Another person moved out into a flat, but then found that the neighbours were a nuisance.

This did not mean in either case that this was a 'wrong' decision, nor that the person was incapable of making a decision. Both people wanted to try things out first, before they were ready to decide what was right for them.

Accessible information was a key issue in 'taking practicable steps'. Many of our participants talked about information that they had found difficult to understand, which left them feeling 'incapable' of making a decision. This had happened in job centres, in review or transition meetings, and certainly in child protection proceedings. Parents who had had dealings with child protection officers spoke about feeling 'scrutinised'. They had to prove their capacity to provide appropriate care, before they could make a decision about their own future:

*Decisions were made behind our back. We were scrutinized all the way through. It started off and it seemed to get worse and worse. And it seemed like you were being watched all the time and you were afraid to move or do anything because you thought, 'am I doing the right thing here, or do they think I am'.*

These findings have implications for assessments of capacity, which should not result in people feeling scrutinised. Our participants told us that the location and the context were very important when receiving information. People who had supportive groups around them were able to find out about information that made sense to them, and did not feel under pressure:

*I began to find out more about things because I belong to People First. I found out about them through the centre, and they've helped me a lot with the decision making, but I made the final decision. But I had to find the support first.*

### 4.3 Third statutory principle of the MCA

- **A person is not to be treated as unable to make a decision merely because he makes an unwise decision.**

The assessment of capacity should be about the ability of an individual to make one individual decision. It is not about the wisdom or otherwise of that decision. This was perhaps the most problematic principle for people with learning disabilities. In smaller decisions, such as where to go out, or what to eat, people told us that they could make mistakes, and learn from them. However, in larger decisions, they told us that they were often treated in paternalistic ways, and that they had not been allowed to make unwise decisions.

For instance, those supporting the person with learning disabilities were often concerned that financial decision-making should be sensible. They felt that, when someone makes unwise decisions about their finance, this may affect other people as well, particularly family members. Therefore it was very hard to allow people to risk making unwise decisions. One person told us of his first move out of his parents' home into a flat:

*My gas, my electric and water went wrong... I was not paying the bills, I was spending the money on going out, having fun. My social worker came to see me and said, 'right, you're going to move out of this flat and move into this supported living home'.*

He felt he had had no control over the decision about moving into a 'supported living home', because he had failed in managing his money. However, he pointed out that he could do these things if he had the right support. Part of the problem he faced was that he could not understand the bills he had to pay, and needed better accessible information about his household finances.

It was also easy for others to judge that someone was making an unwise decision, when in fact they had decided something very sensible. People with learning disabilities themselves were often very unconfident in defending their own decisions, as this person said:

*I don't know if I could have said 'no' to the job. I'm very used to other people making decisions for me.*

One of the parents in our study talked about the situation where she had got married, and was already pregnant. According to her, this resulted in her parents taking over responsibility for her life:

*Because we've both got learning difficulties it was my dad who had to try and make me understand. And from then my dad had a load of court cases .*

Our evidence showed how the inability to make decisions was naturalised into the thinking of people with learning disabilities themselves. However, in extreme situations, people told us that they did know what they wanted, and could speak up for themselves. For instance, one person told us that it was assumed that she could not make a sensible decision about access to her estranged father, since she had been very emotionally involved. However, eventually people did listen to her, and accepted the wisdom of her decision.

Finally, it should be noted that it was not only people with learning disabilities who were accused of making 'unwise decisions'. In fact, people told us about many instances where professionals and family members had made the wrong decision on their behalf, for instance about housing or about their job. It would seem from these examples, then, that there was a strong tendency to associate 'lack of wisdom' with learning disability itself, and to assume that people's decisions could not be sound. However, the main points to emerge were these:

- People told us that they had often made the right decision, in the face of contradictory advice.
- People wanted (and were seldom given) the right to make mistakes and to learn from their mistakes.

#### **4.4 Fourth statutory principle of the MCA**

- **An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.**

The fourth principle of the Act relates to 'best interests' decision-making, where a person has been deemed to lack capacity for a particular decision. The following checklist is non-exhaustive (there is a longer list in the MCA and guidance), but contains some things to consider in working out what is in a person's 'best interests':

- consult friends and family
- involve the person as far as possible
- take into account any advance wishes
- consider, for example, emotional, religious or cultural factors

However, some of the stories we obtained from people in the three groups illustrated some decisions which were clearly made without people's 'best interests' in mind.

a) One person, for instance, had been persuaded to move into a house with another person with learning disabilities, whom he previously did not know. He found that this person was very different from himself, and that he had a good deal to learn about how to manage domestic life. While our participant was very willing to support him in learning these skills, he had to argue the case for many months before his care manager and service provider would listen to him and respect his own decision about his needs.

In this case, the person with learning disabilities knew exactly what his own best interests were, based on a high level of self-awareness:

*I'm better on my own. I did realise that before, but they know it now. I didn't like (sharing) when I was a child. I used to share with my brother, and I did need a bedroom on my own. So that went back to over 20 years ago.*

His problem was in getting others to listen to him; we shall find in Section 5 that decisions by service providers and care managers were often made for pragmatic reasons.

b) One mother with learning disabilities had been involved in successive relationships with abusive men and had been seen as a 'vulnerable adult' and in need of protection from paedophiles. Therefore, she was advised, in her own best interests and in the interests of her children, to leave the man she felt she needed. If she had decided for the man, then she felt she would have lost her right to look after her children.

We could see from our data that many decisions involved compromises between the best interests of one person and often many others. In these instances, where someone cannot speak up so well for themselves, an independent advocate was vital. The MCA makes provision in some situations for advocacy for people who are deemed 'incapable' of making a decision by themselves. However, there would be a strong case for recommending advocacy in many other situations. For instance, we found many people who were perfectly capable of making decisions, but nevertheless needed advocates in order to enable their views to be heard, either with professionals or within the family, as was the case with this woman:

*If I hadn't liked the advocate I would have been able to say 'no, I don't like her'. I met her at the day centre when she popped in to introduce herself to me and have a little chat about what was going on at home.*

#### 4.5 Fifth statutory principle of the MCA

- **Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person's rights and freedom of action.**

The principle of 'least (or most) restriction' was reflected in many of the stories we were told. In fact, several people with learning disabilities gave us examples of decisions in which they had been advised by others to follow the 'less restrictive route'.

a) For instance, one couple who already had children had wanted to opt for female sterilisation, but were advised to accept male sterilisation instead. This

proved to be good advice, since it was later reversible, and illustrates well that taking a 'less restrictive' option is often advisable.

b) Another person told us that he had been advised to get engaged to his girlfriend, rather than to get married. This was an interesting example, as the MCA does not apply to marriage – anyone has the right to make their own decision about marriage. Nevertheless, we found it was a key area for people with learning disabilities and their families.

c) A man who wanted to work in an office was advised to do a work placement first, so that he could keep his options open.

Despite these positive examples, many participants spoke of feeling restricted in general, simply by being a service user, and having to fit in with the routines of service provision. One person who wanted to see his girlfriend found that he had to fit in with two service-led routines:

*I see Lucy whenever I can, but she's got to fit in with her member of staff and I've got to fit in with mine.*

Another person felt that his decisions had to become complaints in order to be heard, and a third person described very eloquently what it felt like to be a 'service user':

*It's all red tape and things, there's too much of it. You have to go through the social worker, the mental health team and those lot whether you want to or not. Because of the nature of your ability, and you've been registered disabled since you were born, they just presume that you need the help of a social worker and third parties and police and all that business to get where you want to go.*

People with learning disabilities said they were only able to make decisions within the confines of this service system, and it would seem, then, from this evidence that the Mental Capacity Act has much work to do in challenging attitudes about autonomy and Learning Disability, attitudes that lie at the heart of Learning Disability services.

#### **4.6 Summary of the principles of the MCA in relation to decisions made by people with learning disabilities**

In summary, the stories told to us by people with learning disabilities fell short of the principles of the MCA in several ways.

- Despite their evident capacity for decision-making, there were several instances where people felt they were left out of decisions or that others had spoken for them.
- People were sometimes judged to be incapable of decision-making, simply because they had a learning disability. There was an issue of 'low expectations'.

- People were seldom given good, clear information about the options available to them, although many people did value the chance to actually see the options, to try something out, or to look at alternatives.
- Parents and carers tended to be active on their behalf, but only involved the person with learning disabilities at the end of a decision-making process.
- There was often some confusion between being capable (in terms of skills) and being capable of making a decision. This led to people being restricted in their choices, because of possible unwise decisions (or having behaved unwisely in the past).
- There were occasions on which decisions had been made on pragmatic grounds, and were not evidently in the best interests of the individual with learning disabilities.
- People with learning disabilities generally felt restricted by the service system itself, which (to some people) appeared to run counter to their own autonomy.

These problems indicate that the MCA should have a major impact on everyone concerned with major life changes for a person with learning disabilities.

What was true for the majority of our participants, as summarized above, was also true for parents with learning disabilities. However, for parents with learning disabilities, there was a direct conflict between the rights of the parent and the rights of the child. It was unclear from the stories we heard what the effect of the MCA would be on this area. It could be that Child Protection laws would take precedence, and so test cases will be needed to explore this. This was certainly what our participants felt. In the arena of Child Protection, parents told us that their parental knowledge and ability to fulfill their parental responsibilities were scrutinized in relation to the supremacy principle in child protection, in which the child's needs are always paramount. The parents felt that they lost control of their family in these circumstances.

- Parents did not have appropriate information, for instance regarding contraception to make informed decisions or to contribute to meetings regarding the welfare of their children.
- They were not listened to.
- They were not respected and were 'treated like children'.
- They were assumed to be unable to parent appropriately because they had a learning disability.
- They had decisions 'made behind their back'.
- Their ability to engage with services was impacted upon by their wider family situations – i.e. family members locating and providing them with information and engaging in court proceedings on their behalf or providing a negative family context which went against them.

## **5. How does care management practice match up to the principles of the MCA?**

Although social services departments would adhere to the principles of advocacy and self-advocacy, it is often difficult to ensure that this occurs in practice. In a regional study on commissioning carried out for LIFT South West, 28 cases of care management were examined, in four local authorities, by means of record searches and interviews with care managers. Ten had moved into a residential care placement, thirteen into non-residential situations, and the remaining five had stayed in the parental home, with day care or short-break packages. Twelve of the people who had moved were followed up with interviews in their new placement, and in most cases we also talked with their family carer. These data were collected from September 2006- July 2007, and so were prior to the implementation of the MCA. However, many of the experiences outlined in these care management cases resonate with the guidance provided in Chapter 3 of the MCA's Code of Practice: How should people be helped to make their own decisions? (DCA, 2007. pp 29 – 39). In the following sections, we outline how messages from the MCA's guidance would have applied in these cases.

### **5.1 Protecting a person with learning disabilities from disappointment**

The first statutory principle of the MCA is that a person must be assumed to have capacity unless it is established that they lack capacity. However, we found that in 2006-7, people with learning disabilities were often assumed not to have 'full capacity', but to be involved in decisions about their own life at a rather late stage. This was for a number of reasons.

From the interviews with care managers, there were many reservations expressed about involving the person with learning disabilities too deeply, or too soon in the process. 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, others had decided for him that his interests and motivation needed to be expanded. We found that care plans and particularly college reviews, routinely emphasised the need for independence, and prioritised this over free choice. It was hard for people to choose to 'do nothing'.

It would seem then that the first statutory principle of the MCA was regularly being flouted within standard practices of care management, immediately prior to implementation of the Act. People with learning disabilities were assumed to have a voice, but in practice, the care manager tended to talk with the parents rather than the person themselves. In their turn, parents tended to sort out all the options and make a decision before involving their son or daughter.

- A young woman who was very vocal and assertive in general, was held back by her parents from making her own enquiries about moving on from the family home. They wanted to ensure first that the options available were suitable, before she viewed them.
- Another young man who was returning from residential college was 'placed' in a supported living home, and was not even taken to see it until the decision had been made about his move. He had not seen any alternative places to live, and when asked what would have happened if he had not liked it, the care manager said that: 'he could have said no'.

There was little these people could do to really have a voice in the decision about their move.

## **5.2 Lack of information about options available**

The second statutory principle of the Act is about taking 'all practicable steps' to help people make a decision. Additionally, the Act's Code suggests that involving people who the decision maker trusts may be one way to enable decision making (DCA, 2007, p.38).

As we saw in the stories from the current project, 'practicable steps' to involve people in decisions could mean many strategies. People needed good information they could understand, and they often needed to have practical experience of the outcome of a particular decision. For instance, if deciding whether or not to move, they may need to try out a particular option. However, from the evidence we found about care management practice, information about housing options was in very short supply, both for the person with learning disabilities and for their carers. Further, eight out of twelve of the people interviewed felt that they had not got to know their care manager sufficiently. Parents echoed this sentiment, and felt that a better relationship with the care manager would really help their son or daughter to be actively involved in decisions:

*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]*

Where there was a good relationship, people with learning disabilities both remembered their care manager and valued the 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]

### **5.3 Decisions driven by availability of placements**

The Act's guidance would recommend getting to know people to find out about their communication strategies to ensure they were participative in the decision making process (DCA, 2007, pp34-35). While care managers in our study would have liked to work in this way, in practice, they appeared to be driven by two factors. The first was about the recorded needs of the individual, and the second was about the pragmatics of what was available locally.

1) From the record searches and care manager interviews, we asked specifically what had been the most important factor in leading to the decision for the person with learning disabilities. All the care managers rated 'the person's needs' above financial considerations or parents' needs. What tended to happen, however, was that the decision was virtually made first by parents and care manager jointly, before the person with learning disabilities got involved or had a voice.

2) The driving force behind deciding on a move, whether to a residential home or into supported living, was often the availability of a placement. 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]

In this climate, the practicable steps to involve a person in the decision were seldom taken. With people who did not communicate verbally, there were blanket assumptions expressed by care managers that the person would not be able to speak for themselves. Although there were several instances of care managers spending time in getting to know the person, generally the major part of their work was in communicating with families, as was evident from the 'running record' of work done on each case.

## 5.4 Involving the person by means of person-centred planning

The Act's Code of Practice focuses on the importance of the timing and location when supporting decision making (DCA, 2007, pp35-37). People need to have settings and support which lead them to feel relaxed, confident and comfortable. These factors underpin the practice of person-centred planning, and so we were interested to see how far person-centred planning was taken into account in the decisions about care management.

Seven of the twelve people with learning disabilities who were interviewed 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. This is in effect supported decision-making in practice. The existence of PCPs and their influence in care management is reflected in Table 3 below:

**Table 3: Person centred plans and residential outcomes**

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

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.

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 remembered the name of her advocate some six months later.

Parents who had been involved in person-centred planning with their son or daughter spoke of 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 could tell whether something was 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. The importance of having support from other people is also outlined in the Code of Practice (DCA, 2007, p.37), and this work would add weight to that. However, we could also observe that this type of support for decision-making was only occasionally taken into account by care managers themselves.

## **5.5 'Best interests' decisions**

It will be recalled that the study from which these cases are drawn (Williams et al., 2007) collected data about care management practices just prior to the MCA. Therefore, none of the people we followed up had had an assessment of capacity, formal or informal. Nevertheless, seven of these individuals were deemed to have 'high support needs', often with communication needs, behavioural needs and a physical impairment combined. These individuals, as noted above, were sometimes involved in decisions through the efforts of their parents, friends and circles of support. However, from the care management point of view, the decision was very much a 'best interests' decision, in the sense of the MCA. The following people had all had decisions made for them, which were evidently in their own best interests:

- One person with multiple needs was deemed to be best placed in a specialist centre which had sensory equipment and expertise.
- Another person was going to be supported to set up home with other young people who had returned from residential college,
- A third person was receiving direct payments in order to go out locally and access activities in the community.

In all these cases, it could certainly be said that the 'less restrictive' principle had been adhered to, since these people were living in their own communities, they were able to pursue interests and to keep up with familiar friends. All

these things meant that their options for the future remained as open as possible.

However, it ought also to be noted that the more people with high support needs than others moved into residential placements; the most important variable in predicting a 'residential outcome' was the number of needs. Those with higher numbers of needs noted on their care plan (between 7-9 'needs') were more likely than others to move on to a residential placement, as is shown in Table 4.

**Table 4: 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	<b>7</b>	<b>9</b>	<b>2</b>	<b>18</b>
Move to residential care	<b>2</b>	<b>3</b>	<b>5</b>	<b>10</b>
Total	<b>9</b>	<b>12</b>	<b>7</b>	<b>28</b>

Therefore, those whose capacity is most likely to be in question were precisely those people who tend to go into residential homes. This reflects what we know from other studies. 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). Once within the residential care system, we know that choices for future moves are going to be limited, and no-one who was already in residential care in our study moved out into supported living. There is therefore a good deal of restriction naturalised in the system of allocation of housing to people with learning disabilities, with the most 'needy' often being the most restricted.

### **5.6 Summary of care management practices and potential impact of the MCA.**

In summary, then, the baseline measures we obtained about care management practices fell short of the principles of the MCA in several respects.

- **A person must be assumed to have capacity unless it is established that they lack capacity.**

Seven out of 28 people had decisions made for them, because of their high level of communication support need. Of the remaining 21 people, very few had been involved in decisions throughout the care management process, and many moved to a new home without having seen it until the decision had been made. The MCA would impact on this situation by allowing care managers to be clearer about exactly who should be the primary decision-maker. It would ensure that either a) a person with learning disabilities was deemed competent to decide on their own future living arrangements; or b)

that he or she would need someone else to decide in their best interests; and/or c) that other people were involved in supporting best interest decisions, including on occasions independent mental capacity advocates.

- **A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.**

Care managers communicated most frequently with parents and family members, who (in their turn) often did try to involve their son or daughter actively in decision-making. However, there were very few attempts to provide information about available options for moves, and no accessible information that we found in this study which would have helped the person with learning disabilities to make an informed decision. The MCA would impact on this situation by putting a duty on the care manager to supply accessible information, and to provide proper supports for the person with learning disabilities to reach their own decision.

- **A person is not to be treated as unable to make a decision merely because he makes an unwise decision.**

The 'unwise' decision issue did not explicitly arise, except in one case. However, the MCA would have the effect of ensuring that a person should be supported to move to the area and to the place of their own choice, even if it was felt that this decision was unwise. This could have an impact, for instance, in people learning from their mistakes, and wanting to move to a more suitable place. Instead of closing 'case files' once someone is placed, this principle implies that people's choices should be an ongoing matter.

- **An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.**

In general, care managers' decisions were overtly based on extensive information about the person's needs. However, in reality, the final decision was often made on the basis of necessity, and the vagaries of placements becoming available. The MCA should have the impact of ensuring that decisions about placements are made on an individual basis, according to need, and not according to supply of resources or of placements. This is also the philosophy behind individual budgets (DH, 2006).

- **Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person's rights and freedom of action.**

People who 'lacked capacity' were more likely to be placed in a residential care home. This meant that restrictions inevitably did apply to them, in terms of the freedom they will have to make future choices for a move. However,

there were three cases where people with high support needs were supported to stay in their local community, and to have flexible support, which arguably gave them a wider range of options for the future. The main impact of the MCA should be to ensure that residential homes do not become the option of choice for people with the highest level of needs, who may lack capacity.

## 6. Good practice in supporting decisions (and in assessing capacity)

The 20 people who came to our workshops had all made a major change in their lives, and in most cases this was something positive – i.e. moving house, getting engaged, getting a job. The stories they told us about their decisions were long and involved, as will be seen from the examples of visual decision maps. In most cases, it was very hard to pinpoint the moment at which a decision was made, since a ‘big issue’ decision tends to take time, many encounters and many discussions with different people. A decision only becomes realized when the right opportunities exist – for instance, a decision to move is only a positive decision if a house or flat becomes available. Therefore, it is hard to see exactly the point at which the assessment of capacity would happen for many of these life decisions.

This final section outlines some good practice points in supporting decision-making, from the point of view of people with learning disabilities. All these points are also important from the point of view of assessment of capacity. There are three generally recognised approaches used in assessing capacity (Wong et al 1999; Suto et al 2002). In the status approach a person’s capacity is assessed on the basis of their belonging to a particular ‘group’ - for instance having a learning disability. An outcome approach is based on the decision a person makes - they may then be deemed incapable if their decision is considered unwise. In the third, functional approach the individual’s capacity to make a decision is assessed on a task by task basis, based on a weighing up of their understanding of the task, making a choice and communicating this choice. This third approach is promoted as good practice by the BMA/Law Society (1995) and has been adopted in the MCA .

Under the MCA, a judgement of incapacity is related to a ‘reasonable belief’ that a person is incapable of making a particular decision by themselves. The problem for people with learning disabilities is that there may well be a very low threshold for determining a reasonable belief. What we would propose from the evidence of this study is that those assessing capacity should have a means of showing that they have gone through at least some of the following steps, and recording those actions, before assessing a person as incapable of making a decision. In this section, the bullet points all refer to themes that emerged from this research, which match points made in the MCA guidance about good practice.

### 6.1 Getting information

*You need to put things into pictures, it makes it easier. It helps if you write things down for you. It helps you remember, and not get confused about things. If you wanted to know what you said on a particular day, you can go back and look at it.*

Good information is the key to decision-making and capacity assessment. Without good information, people can easily appear unable to make a decision. Unfortunately, this was a major barrier for many. For instance, our participants mentioned information about housing, money, jobs, contraception or childcare which was too difficult for them to understand. Even more importantly, though, they were often in situations where they did not even know what kind of information might be available, or what they needed to know. What, then, had helped people get good information?

- **Trust**  
People often spoke about knowing the right person to give them information – someone they could trust. This could be their college tutor, a trusted friend, or a support worker.
- **Informing someone that there is a decision**  
People said that the most important thing was to know they could make a decision. Because many people with learning disabilities are used to others deciding for them, the first point in any information must be to help someone realize they can decide for themselves. One woman said: 'They told me I had choices to make, and if I saved my money, then I could choose a carpet. It's really lovely.'
- **Concrete experience**  
Trying things out was often very useful, to get concrete experience on which to base your decision. People had tried out jobs, and particularly valued going to see houses or flats before deciding on a move.
- **Friends and peers**  
Information from friends or peers is particularly valued, especially if they have already tried something out. One person said: 'Loads of my friends move in all the time. Since I've been at the centre I've known about 4 people that are moving to Key Ring'
- **The key points**  
Sometimes there are important points of information that will 'swing' a decision, and it is especially vital to get these across to people. For instance, one person said: 'Once I found out there was pay, I decided to go for the job'.
- **Constraints and outcomes**  
Good information needs to cover the constraints involved in a decision, as well as the alternatives and the possible outcomes. People said they need support to look ahead, and be realistic.
- **Easy information: visual formats**  
All this information needs to be easy to understand. People talked about the advantages of visual information – particularly for helping to plan out the 'pros and cons' of a decision.

- **Repeated over time**  
Information needs to be given over time, and repeated. It is not a ‘one off’.

## 6.2 Alternative choices

*Dora chose the second place she looked at because it had positive points she wanted from a flat; sea views, separate rooms, plus the landlord is nice. She had only compared it to one alternative which was a studio flat, and she was clear she wasn't satisfied with that.*

It was frequently the case in our data that people had received information about one particular choice – for instance, one flat they could move to. The choice was essentially ‘Do you want to do this or not?’ One person had that choice to make about moving in with her brother and his wife, but had no alternatives to think about. It is hard to know about something like that, without trying it out. Therefore, another principle of supporting decision-making is to ensure people have good information about alternative choices.

- **Experience of alternatives**  
Alternatives are never identical, and so people appreciated having time to try out different options. One woman talked about two options for jobs: *‘We worked with teachers in Broadway. They go to the meetings, and we work as support assistants. So we do exactly the same thing as we do here, but we do it a bit different in town. We do the teas and coffees, and we take the cakes and lunches through.’*
- **You can say ‘no’**  
Just because someone has seen alternatives, this does not mean that they have found the right thing for them. A few people told us how important it was to be able to say ‘no’ and to have this decision respected.
- **Changing your mind**  
Another alternative choice is to change your mind. Sometimes a person’s initial decision was very tentative, and when they had more information, or when they had tried something out, they changed their mind. For instance, one person said about her new flat: *‘I loved the view and it was close to work but some things went bad there so I had to move in the end. I had to move out of my house because I wanted peace and quiet. I wasn’t forced into it.’*
- **Choosing both the alternatives**  
Sometimes when people know both the alternatives, they decide that there isn’t a choice to be made – they want both. This happened with a person who was trying to decide between two part-time jobs, and ended up doing both.

## 6.3 Communication

*I phone the social worker, but I don't get no answers. That's because he don't like me, so I've been told. He said 'I've got to come round and see you'. I was going to ask someone to come with me, I want someone there with me.*

Many people with learning disabilities have significant problems in verbal communication, both expression and understanding. Therefore, communication often has to be tailored to the needs of the individual. However, it is important to get communication right across the board. Many people who had good verbal communication nevertheless told us that they had difficulty in getting people to listen to them seriously.

- **More than one person should be involved**  
Communication is about personal relationships. Therefore, it is important to have more than one person communicating with someone about their decision. That way, there is more chance of getting it right. *It's good to get support. There were two people who were involved in helping me to get the job. Ann was the main person. But I thought that I couldn't just rely on Ann. So then I got the tutor involved. When I got her involved, we went to the job centre.*
- **Listening and acting on a decision**  
People told us they were happy with decisions they had made, when others had communicated with them, and really listened and taken them seriously. Good listening is about action, and this happened best in the context of good person-centred planning: *You decide on your goal, and draw it out. Then you break it down, step by step. And people agree to help you with your plan, and then when they haven't done something, you can go up to them and say 'oi, why haven't you done this?' People are signed up to it. And you've got the record of it.*
- **Taking time with communication**  
Some people who came to the workshops needed more time to get their message across. They said that it was frustrating when other people rushed them. They wanted to have a lot of time and space, and a quiet situation.
- **Finding out each person's preferred communication method**  
Those who know the person best will usually be able to give information on how they communicate, whether this is with words, pictures, signs or assistive communication devices.

## 6.4 Who should be involved?

*I'm glad I've come here. The group helps, and it gets me out a bit. I'd give that two stars!*

Decisions are never made in isolation, and people told us of all the conversations they had with family members, friends, staff and others. All these people could be helpful at different times – it depended entirely on the decision being made at the time. The most important thing was for the person themselves to choose who should be involved. One man said this is about *'Nothing about me without me'*.

- **Independence**

Those who communicate with a person about their decision should not have a vested interest in the outcome of that decision. More than one person said that their day centre had been helpful, as staff were independent of the decision being made. One person told us that he had felt very constrained about talking with his home staff about his decision to move: *'because if I'd told them they would have said 'no, you won't move out'. Because they want money, that's why. They have all my benefits and all that stuff, see.'*

- **Advocacy**

Independent Mental Capacity Advocates are only called in for certain situations and decisions. However, there is a far more general need for advocacy, so that people can get their voice heard. People told us about how important advocates were, especially when they were in tricky family situations where their decision had an effect on other people: *'If I hadn't liked the advocate I would have been able to say 'no, I don't like her'. I met her at the day centre when she popped in to introduce herself to me and have a little chat about what was going on at home.'*

- **Being on your side**

Whoever the person is, they should be 'on your side'. Parents with learning disabilities, in particular, had had experience of others judging them. They wanted 'non-judgmental support'.

- **Peer support**

One of the most important groups of people in supporting decisions is one's peer group. This was so for parents with learning disabilities, but also for others. It helped people to think about their decisions when they talked with others who had had similar experiences: *'I began to find out more about things because I belong to People First. I found out about them through the centre, and they've helped me a lot with the decision making, but I made the final decision. But I had to find the support first.'*

## 6.5 Understanding how decisions are made

When supporting someone to make a decision (or assessing their capacity), it is important to understand some of the factors that underpin decision-making. These were the ones that emerged as important themes for our participants.

- **Emotion**

People often spoke of decisions that they had made because of feelings. This did not just apply to relationship decisions. Moving to a new place was often associated with ‘falling in love with it’. In the end, a decision has to feel right, and one person said: *It was more a heart than a head decision.*’ This is true for everyone, and emotion-led decisions are common. They do not necessarily signify incapacity.

- **Family and cultural values**

People make decisions based on their own experience, but also on the values with which they are most familiar. One person, for instance, said that she had decided against an abortion, because of the values she had grown up with: *‘We had the decision to look after it ourselves I never believed in abortion. (it wasn’t a decision to be made) My dad don’t believe in it.’*

- **Timing**

Decisions often took a long time. Snap decisions over important matters should not be expected from anyone. There is often a ‘right time’ for a decision. People may need to put off a decision until that moment comes, as this man said: *‘I had made the decision to move but then I changed my mind because I thought mum was not very well and needed help. I always worried that I wouldn’t like going into a flat because my mum would be upset’.*

- **The right place**

It is hard to make a decision when you are in the thick of things, and people often need to step away from the situation in order to make a good decision. For instance, more than one person spoke about their day service, or day centre, as being the place they could talk to people and think about their lives. This is important, in the context of changes in day services, and emphasizes the need for social support.

- **Building up confidence**

Confidence was a key factor in being able to make a decision. In one of the ‘summing up’ sessions at the end of a workshop, people talked about what gave them confidence. They said it was about ‘achievement’, and that one successful decision could lead to another. They also said that you could learn the skills to make decisions and become more confident.

*I’d never interviewed anyone in my life. I’m glad I did because it’s another skill I’ve gained and no one else did it for me. I’ve got control of my life at the moment, I’ve got more control than I had.*

## 7. Tools for good practice in supporting decisions and assessing capacity

This final section presents the 'good practice' tools that we developed from this project, and summarises the points made in the action workshop with which we concluded our project. The tools themselves are presented at the end of this report, in the amended format incorporating suggestions from the action workshop participants. The three tools we developed from this project are:

- 1) **Who decides?** This is a flowchart for support staff working with someone with a learning disability, intended to help people to think through their responsibilities under the MCA.
- 2) **I decide** This is a bill of rights, designed for people with learning disabilities themselves to help them know what the MCA might mean to them.
- 3) **Good practice checklist** This is a summary of some of the points made in section 6, with additions from participants at the action workshop. It is written as a flexible record sheet, to remind people about good practice and enable them to record what they have done to support decision-making and assess capacity.

Before presenting the tools, we will present the four vignettes we talked through at the workshop, and list the specific points made about each of those examples. We will also discuss some general points about the MCA in relation to people with learning disabilities, in the light of issues raised by our workshop participants, and we will conclude with some messages from people with learning disabilities themselves.

### 7.1 Vignettes discussed in the action workshop

1. **Helen** is a 50 year old woman with a learning disability.



She lives in a supported house. She communicates with simple language. In most cases her support workers think that Helen has capacity to make her own decisions. She has told her support worker that she thinks she has found a lump in her breast. When Helen's support worker explains that this is something that should be checked by a doctor Helen changes her mind and says that she has always had the lump and that it will be OK.

Helen has had a bad experience at the doctor's surgery before. She doesn't like the waiting room there and thinks that the doctor isn't kind to her. Helen's support worker is not sure what to do next.

**2. Stan** is a 65 year old man who lives in a registered care home with 3 other men.



He has lived in the same place for 20 years but the home is closing down. He does not have any living relatives. He counts the other men in the care home as his friends. He doesn't use words to communicate. His support worker helps him to communicate choices with the use of picture symbols. Stan indicates a preference by pointing to picture symbol. One of the other men from the home is moving to a supported house and has

said that Stan would like to move there too.

Stan does not respond when you ask him about moving to the supported house too.

**3. Jenny** is 25. She's moving from her parent's house to a supported house. Jenny is keen to have her own budget to pay for her accommodation, bills and daily living expenses. Before she got the place in the house she did a person centred plan in which she said that if she had enough money she would like to go to New York. She says that as soon as she gets her own budget she will start saving for this. Her carer says she shouldn't handle her own money and that trip to New York would be a waste.



**4. Jim** is a 21 year old man.



He lives at home with his mum and younger brother. He has started to go to a nightclub for people with learning disabilities once a week and has met a girl called Mary. Mary lives quite independently in her own flat with a support worker who visits her each day.

Mary has asked Jim if he would like to spend the night at her house after the next nightclub night.

Jim's mum is worried what might happen if Jim has sex and gets Mary pregnant. She doesn't think that Jim understands what it means to have a relationship and therefore doesn't have the capacity to decide whether to sleep with Mary. She doesn't think that Jim should stay at Mary's house and is refusing to let him go to the nightclub any more.

### **Discussion about vignettes**

The four vignettes given above provoked some very interesting discussion about the dilemmas involved, and some creative ideas for good practice. In discussing these stories, we asked the groups to go through our draft checklist (p. 55) and to suggest amendments. On the whole, the groups found that the checklist did help them to consider their response to the story, but they also made some useful points which are now incorporated in the checklist. This is a brief summary of points raised in each discussion.

**Helen's story** was a particularly difficult and sensitive one, which posed many dilemmas. People with learning disabilities are often shielded from the information they need to have, in order to make informed decisions. For instance, the group discussing Helen's story needed to know about the possible outcomes of her decision not to go to the doctor.

However, the group also tended to highlight the practical and supportive steps that should be taken, to ensure that Helen became more comfortable about the decision. Much of the discussion was about how to ensure things turned out right, rather than leaving people on their own to make an impossible decision. This is totally in accordance with the MCA, which urges us to give every type of support to people to make their decision. Therefore, the group felt that they would try to remove the barriers of fear which surround a visit to the doctor's surgery. It might be possible for the doctor to visit at home, for instance. In any case, the practical support needed to be given in small steps:

- 1) Getting to the doctor and feeling confident (Find out why in more detail)
- 2) Could take lots of visits to meet the doctor
- 3) Different doctor
- 4) Support worker talk to doctor

The dilemma here, of course, was that Helen may not have a lot of time to make this decision, if the lump in her breast turns out to be malignant. Therefore, there may be some decisions which have to be supported in very sensitive ways. Some participants in our workshop felt that Helen did need the 'hard' information about the potential issues in having a lump in her breast, and that she had a right to decide not to have treatment. Others felt that the information would scare her, and so her decision would not be well informed. As with many of these scenarios, people felt that the checklist of good practice may help to think about what to do, but that each person's situation is

bound to be different. Helen's supporters would need to be both sensitive and speedy in their response to her dilemma.

**Stan's story** was slightly easier, but it was felt that someone like Stan might have great difficulties in getting his own feelings across to others. This does not necessarily mean that he is 'incapable' of making the decision about moving; his story highlighted how easy it is to make assumptions about someone's wishes, and to behave in a pragmatic way. If the other residents are moving, then Stan moves too!

The group discussing Stan consisted entirely of people with learning disabilities. They felt firstly that it was his right to have information about *why* the home was closing. When it was pointed out that he may have severe communication difficulties, they came up with some very good ways of supporting him. First, they said, it would be good to observe him – and especially to observe his body language. They suggested making a video of him in his present home, so that they could understand better what he likes and what he does not like. They also said that it would be important for him to visit the new places he might move to, and that they could make videos there as well, so that he could look back at them. We added some of these ideas to the checklist of good practice.

The group also felt that Stan would need friends who were 'independent' of the house where he lived. This might mean an advocate, or a circle of friends. In either case, they felt he would need time to make his decision in a supportive and friendly way. As the group said:

*'Give him time. Remember – you're playing with his life'*.

**Jenny's story** also provoked a lot of discussion. It was felt that Jenny's decision on whether or not to go to New York led to many other, smaller, decisions that she would have to make. As with Helen, the group concentrated on practical steps that would help Jenny to learn and to work out what she could do. For instance, in this case, there may be information she would need about the costs of the trip, and there may be good ways of helping her work out her own budget, so that she would know what the trip would entail.

However, the group was very clear about Jenny's right to make this decision herself, even if it turned out to be an 'unwise' decision. As they said,

*'If she wants to do it enough, she'll make sacrifices'*

At a pragmatic level, Jenny's carer of course needs to be involved. The scenario stated that her carer was against her considering the trip to New York, and so Jenny's carer needs to be convinced that Jenny has made a sensible, considered decision. The group felt it was quite likely that Jenny's carer also needed information about going to New York, and potential costs. Sometimes, it was felt, a person-centred plan can help with this type of decision, since it helps people to plan things out in a more considered way,

and to convince others that they have thought seriously about what they are doing. This group particularly emphasised the need to add pointers about 'practical steps' to the checklist.

Finally, the fourth group who discussed **Jim's story** consisted almost entirely of professionals. They particularly drew out points about how to separate out the different decisions to be made. Jim's mother was reluctant for him to go to the nightclub. However, it seemed to the group that there were three decisions that needed to be unravelled:

- 1) Whether to go to the nightclub
- 2) Whether to stay over with a woman friend
- 3) Whether to have sex

The group felt that Jim's mother had made a possibly unwarranted assumption, that Jim would have sex if he stayed with Mary. However, the scenario rang true for many in the group, who had come across similar situations. They felt that it was often a matter of compromising with family members who may not want their son or daughter to make decisions at all. In the end, Jim might have a difficult decision to make – between his rights to have a relationship, and his continued good relationships with his family.

Again, this group thought of many practical steps which might help Jim to understand the issues, and to work out whether or not he wanted a relationship. For instance, he could go to a relationships group, or he could simply meet people who did have partners. They also felt that Jim would definitely need an advocate:

*'Jim has got a job to do, to impress on his mum that he has got the capacity to make these decisions himself. But if you give him the support to do all those things (in understanding relationships and sex) then that helps with his mum'*

This group went through the checklist in some detail, and suggested changes in wording. For instance, the phrase about 'becoming confident' was changed to 'feeling confident', as they felt that no-one is confident all of the time! The one person with learning disabilities in this group also suggested that gender may be important, and that Jim would need to talk with a man.

## **7.2 Discussion**

### ***Problematic issues about implementing the MCA***

During the course of the action workshop, there was some interesting discussion about the MCA in general. Much of this raised problematic issues, particularly around the practicalities of the scenarios given above. For instance, although the MCA states that people have a right to make 'unwise decisions', this is very hard to reconcile with practice. The very act of making an unwise decision (e.g. not going to the doctor when you need to) seems to be a symptom of incapacity for many people; in practice, it is hard to distinguish between someone who does understand, but makes a 'bad'

decision, and someone who simply does not understand the consequences well enough. Therefore, practitioners felt that they would still implement practical, supportive steps to enable people to reach the 'right' decision. For instance, a person considering sex would be introduced to sexual health training and contraceptive advice; a person wanting to spend a lot of money would be given budgeting advice and education. In effect, it was felt that people could not make a properly informed decision before receiving all this advice and training.

Another, possibly related, issue was the views of key people who surround the person with learning disabilities. In real life, people are often dependent on family members, supporters, or others who feel responsible for their welfare. Therefore, it is very hard for the individual (even with support) to stand against the wishes of a key person in their life. Workshop members felt that there is often a necessity to compromise, and perhaps to provide training and support for family members, as in the case of Jim's mum (see Scenario 4):

*The reality is that, after the work's done, and they say that Jim has got capacity, and that his mum says she is not going to let him, then he won't be able to stand up to his mum.*

These points could be expanded. From the evidence of the maps of decisions in our original workshops, we know how complex and multi-faceted people's lives are. The MCA tends to paint a picture of the decision-maker as an autonomous individual, whereas in reality there are many other people and issues involved in a person's life. It is a mistake to think of some decisions in isolation and it may sometimes be necessary to re-think what the decision actually is. For instance, in Jim's case, his decision might actually be between listening to his mother and disobeying his mother, rather than between having sex and not having sex.

### **Good practice**

As a consequence of the above discussion, it was felt in our workshop that practical steps need to be taken to support good decisions – and that these steps should not just relate to the person with learning disabilities. It might well be that practical steps need to be taken to support others around the person. Workshop members were particularly keen to discuss the small steps that could be taken, in stages, to support someone's ability to make a decision. However, it was also felt that people need to take risks, and should not be shielded from risk, disappointment or bad news.

*X: People with learning disabilities need to have risks in their lives, and see if they can test the boundaries.*

*Y: But how do we learn to make decisions? We make small decisions from a very early age, and we learn by making mistakes.*

The main principles of good support centre around trust; people with learning disabilities all spoke up for having someone they knew and trusted. However,

again there is a dilemma for many people with learning disabilities, since the people they know best might in fact have a vested interest in the decision to be made. In practice, it is very hard to have someone who is 'on your side' and really advocates for you, without that person also having a keen interest in you making the 'right' decision. The MCA only makes provision for an independent Mental Capacity Advocate in certain very restricted circumstances. The need for advocacy, however, is far greater – particularly where people have close family members, an advocate might have an essential role in listening and taking an independent view of what the person really wants.

### ***Reflections on the Mental Capacity Act***

The outcomes of this project, and indeed the recommendations made about the MCA in the Code of Practice, all reflect what is simply 'good practice' in supporting people with learning disabilities. There is nothing which should surprise, or indeed did surprise, people in our workshops, and the MCA does not necessarily change anything about providing good support. The major effect of the MCA is simply to ensure that we are more explicit about the decision to assess someone as *incapable* of making a particular decision. However, there was some worry that the MCA might make decisions too 'official', and might surround the person with learning disabilities with yet more red tape.

*People with learning disabilities should be able to do things, without thinking about the Mental Capacity Act. You should be able to make a decision without having to think about that – it's only when things become really difficult.*

There was some discussion about when record keeping, for instance, would be necessary, and it was felt that we should only keep records about the larger, or more controversial, decisions. The MCA should definitely not promote a 'tick-box mentality', in which staff are most concerned to cover and account for their own actions. While this is sensible, it poses yet another dilemma. How do we know when a decision is a small, ordinary one, or a major one? In reality, there is a hierarchy or spectrum of decisions and this study has shown clearly how one decision may lead to another.

The outcomes of this study are, in the main, about reconciling some of these practical issues with the MCA guidelines. What we trust is that the checklist and models we have drafted can be used flexibly, to ensure that people are reminded of how we all make decisions – with good support, trust, time and plenty of information. The MCA guidelines talk about 'reasonable belief' of a person's incapacity. However, it is only once we have ensured good, in-depth and quality support, that we are really entitled to judge whether a person can make their own decision.

### 7.3 Conclusions and recommendations

The MCA has not yet started to have effect for most people with learning disabilities, and so we cannot yet tell whether the current picture of decision-making will change over time. This will depend largely on case law, no doubt, and the extent to which people are alerted to the provisions in the MCA. This study has underlined the need for practical training about how to support decisions and assess capacity.

The current study helped to serve a purpose in spreading knowledge about the MCA, but it is still unclear whether and how the MCA will be able to tackle the ingrained, naturalised assumptions of incompetence that underpin so much of Learning Disability services. In many respects, the issues about the MCA are the same as the issues in Learning Disability services generally. *Valuing People Now* (DH, 2008) urges a move towards personalisation of services, and recognises that change is needed. These changes are very fundamental to the way people with learning disabilities are treated as 'service users'; at present, incapacity is taken for granted, people are often restricted by service provision, and decisions are made for people. Therefore, future research about the MCA goes hand in hand with future action and development projects relating to choice and control, workforce development and individual budgets.

More research is needed, with a longer time-frame, to monitor:

- a) the development of assessment of capacity frameworks within services
- b) case law as it happens
- c) the take-up of recommendations from the MCA by professionals, including social services departments, doctors, lawyers, mainstream employment services and others.

### 7.4 Final messages from people with learning disabilities: 'Nothing about me without me'

At the end of our three workshop days, we asked people with learning disabilities what messages they would have for SCIE, and for the MCA. These were the three 'headline' points, that were the most important things for them.

#### 1. Trust us

We can make decisions for ourselves, and we are more competent than you think.

*It's how we can change people's minds. And it's how they treat people with learning difficulties. As a group, we should be treated equally and we should be in control of what other people are saying.*

#### 2. More people should have person-centred planning

The best way to make decisions is with people you trust, who can help you to understand things, and will listen and make things happen. All the best points

about person-centred planning are also the best points about supporting decisions.

*You need to put things into pictures, it makes it easier. It helps if they write things down for you. It helps you remember, and not get confused about things. If you wanted to know what you said on a particular day, you can go back and look at it.*

### **3. Together strong**

The best way to get support for decisions is to know other people who have the same experiences.

*I'm glad I've come here. The group helps, and it gets me out a bit. I'd give that two stars!... I began to find out more about things because I belong to People First. They've helped me a lot with the decision making, but I made the final decision. But I had to find the support first.*

## Model 1: Who decides?

Guide for care staff working with people with learning disabilities: points for practice in applying the Mental Capacity Act.

Do I have to think about the Mental Capacity Act at all?

Mac has a learning disability: this **MIGHT** affect his capacity (If he does not have any 'impairment of, or a disturbance in the functioning of, the mind or brain.' then he won't fall under the Act – although a 'disturbance' could include a temporary state of drunkenness, etc).

Does Mac have a big decision to make?

Should I be involved in this?

The issue may be about Mac's ability to do something, NOT about his decision.

If you are the person who needs the decision made, then you are the 'decision maker'. But if you are paid to support Mac, then you will have a role too: read on!



If the answer is yes – that Mac has got a decision to make, and you have got a role in helping him, then just go ahead and support Mac to understand and to make his own decision if possible. In most smaller decisions, nothing formal will be necessary. People can just carry on and decide things!

**Look at our checklist  
which will help you keep a record.  
It is based on what people with  
learning disabilities told us about  
things that help them.**

**1. Give Mac good, easy information about  
the decision he needs to make.**

**2. Make sure that Mac knows  
the options he has**

**3. Give Mac a lot of good chances to  
communicate about his choices**

**4. Make sure Mac has a chance to talk  
with different people about his decision**

**5. Remember that we all make decisions  
because of our emotions, our values, and  
in the right time and place.  
We need to be confident!**



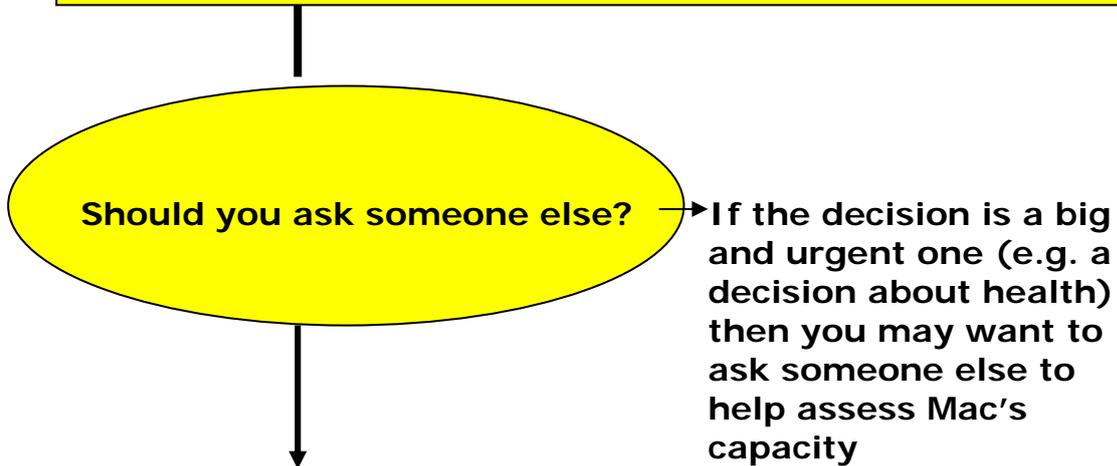
If, after trying all these things, you are unsure about Mac's 'capacity', then you need to ask whether you've got evidence for these things:

- Has Mac shown you that he can understand the things you've told him or shown him?  
YES/ not sure/ NO
- Has Mac shown you that he can remember these things?  
YES/not sure/NO
- Has Mac shown that he can use this information to make his decision?  
YES/not sure/NO

If you say 'no' to any of the three things, it may be that Mac might lack capacity.

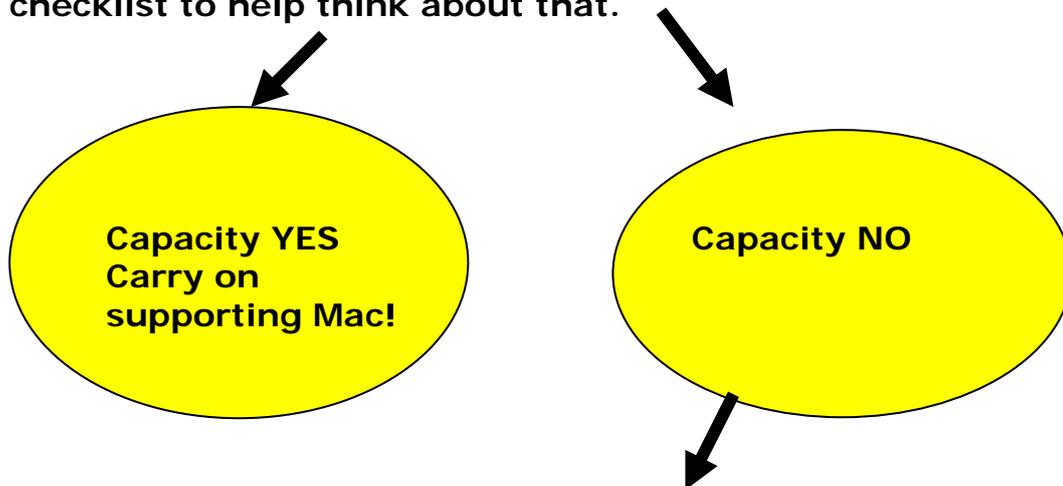
- Can Mac communicate his decision in any way at all?  
YES/not sure/NO

If Mac cannot communicate his decision, then this may also be a supplementary reason to think that he lacks capacity.



If the decision can be taken over time and you have a role in supporting Mac (e.g. to move house), then you may have to say why you think Mac lacks capacity.

There is then a decision about whether Mac has capacity. In either case, it is good to keep a record of the things you have done, and the evidence you have. You can use the checklist to help think about that.



Someone then needs to make a 'BEST INTERESTS' decision for Mac. It is best if this is someone who knows him really well, or is a close family member.

**Things to think about:**

**IF... the decision is about managing finances or property and affairs,**

**IF... the decision is very difficult, or there is disagreement about Mac's capacity,**

**then you may need to apply to the Court of Protection, for Mac to have a court-appointed deputy to manage his affairs.**

**If Mac a) does not have a close family relative or carer, and b) he is facing a decision on a long-term move or about serious medical treatment, then he will qualify to get an IMCA (Independent Mental Capacity Advocate)**



**Making a BEST INTERESTS decision  
for Mac**

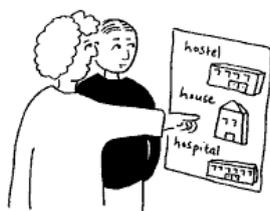
The checklist we have given you also applies to 'best interests' decisions. If you are the person making the 'best interests' decision for Mac, you will still need to think about all the things in our checklist. But you should also look at the guidelines in the Code of Practice, which tell you that you should:

- encourage participation
- identify relevant circumstances
- find out the person's views
- avoid discrimination
- assess whether the person might regain capacity
- consult others
- avoid restricting the person's rights

**Model 2: 'It is my decision'**  
**My rights under the Mental Capacity Act**



Do I have a decision to make?



I may need to decide about moving house.



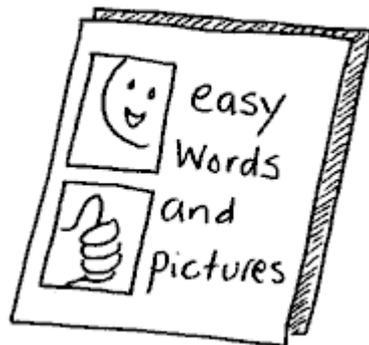
Should I go for that job?



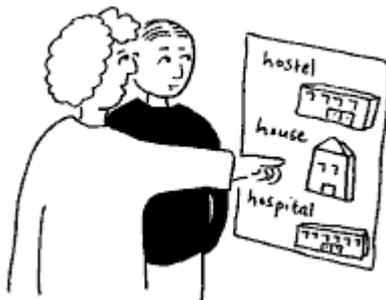
Shall I go and see the doctor or go into hospital?

There are lots of decisions, big and small.

1. I have a right to choose people I trust, who will help me decide.



2. I have a right to have good easy information



3. I have a right to know about my options



4. I have a right to talk to different people about my decision, and be listened to



5. People should communicate in the way that works for me



6. I should have time, and feel relaxed about things.



7. I have a right to change my mind or say 'no' to all of it.

After all this, if I still don't understand how to decide, I might want someone to do it for me.



When someone makes a decision for me,



1. I have a right to be involved as much as I can.



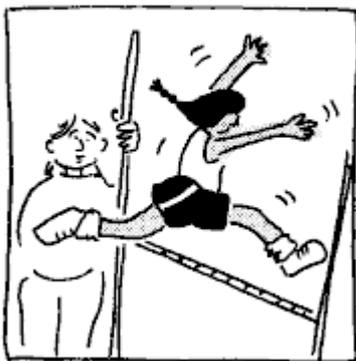
2. The person who helps me must find out what I want.



3. I have a right to get a decision which is good for me.



4. The person helping me should ask a lot of people who know me well.

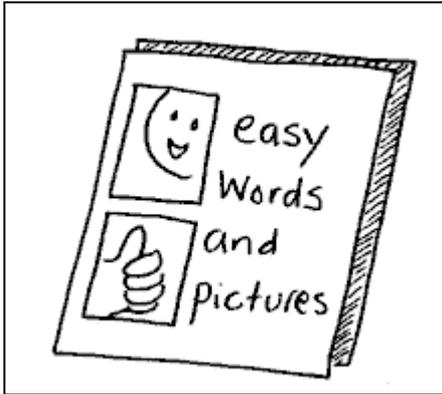


5. I am free to change things if I want in the future

### **3. Good practice checklist : ‘Listen to what I want’**

This checklist is intended to help people who are supporting someone with a learning disability. It contains good practice points that came from the stories of people with learning disabilities themselves. It is no more than good supporters have always done! Here are some health warnings about using checklists like this one:

- Do use this checklist in a flexible way. Adapt it for your own needs.
- Never feel constrained by a checklist. It is not meant as a list of tick boxes. It's to give you good ideas.
- It's a good thing to keep a record of what you've done to support someone in making bigger decisions.
- You could show how you've supported them with this list and your notes.
- If you've done all these things, and the person can't understand, then they may be incapable of making this particular decision.
- Then someone can help them, by making a decision for them, in their 'best interests' . This should be someone who is close to them, and someone they know and trust. They should also follow the guidelines on this checklist.

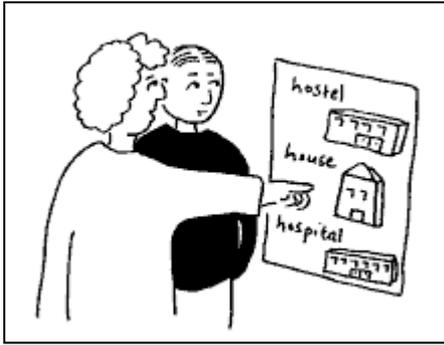


## 1. 'I need good information'

### Things for you to think about

- How will you make sure the person knows that there is a decision to be made?
- Can you think of ways to give easy information about the decision (pictures, photos, videos, other people....)?
- Have you thought about ordinary sources of information (e.g. travel agents, estate agents)?
- Does the person have information from their friends and peers?
- What are the key points about outcomes of the decision that you should explain to the person?
- What are the key constraints on the decision that you will explain?
- Have you thought about the right time to talk to the person about their decision?
- Can you allow enough time, so you can talk about it and go back to things as often as is needed?
- Has this person got a person-centred plan? Could you help him or her to do one?

<b>Date</b>	<b>What I did</b>	<b>How it went</b>

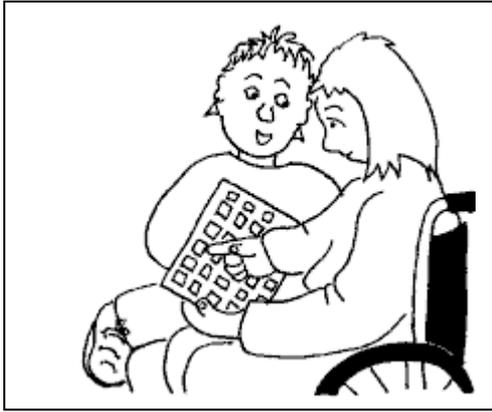


## 2. 'I want to know about my options'

### Things for you to think about

- Does the person have a chance to try out different alternatives?
- Do they have the option to say 'no' to both the alternatives?
- Have you explained that they could change their mind?
- Do they know they could choose both the options (if that is true)?
- Is it possible to have some real experience, so the person can make their decision? (e.g. visiting somewhere, trying something out)
- Are there ways of giving practical support so that the person learns about things in a safe way, step-by-step?

Date	What I did	How it went



### 3. 'I want you to communicate in the way that works for me'

#### Things for you to think about

- Has the person you are supporting had a chance to talk to others about his or her decision?
- Have you used ways of communicating that are right for the person you support? (e.g. signs, gestures, pictures)
- Are there particular ways this person has, to show you what he or she wants?
- Have you asked other close people how the person communicates?
- What times of day are best to talk?
- How long does it take for this person to get relaxed and to understand things?
- Have you considered observing (or video recording) the person in different situations, to see what they are happy with?

Date	What I did	How it went



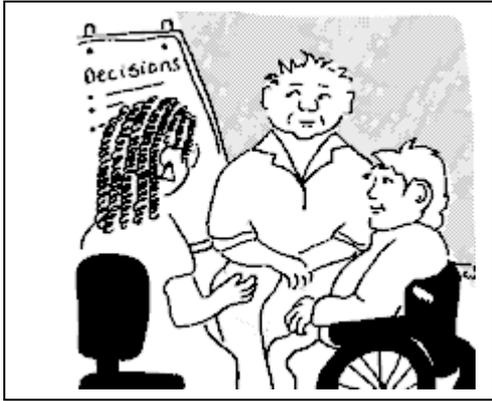
#### 4. 'I want to talk with different people'

### Things for you to think about

Decisions are mostly made with other people.

- Are there people who this person specially trusts? If so, could they get involved in supporting this decision?
- Could this person have a circle of support to help him or her?
- Who are the other people involved? Do they have a vested interest themselves in the decision, or are they independent?
- Does the person have an advocate, who is really there just for him or her? Does the person have people who are 'on his side'?
- Does the person have peer support?
- Has the person got someone of the right gender to talk to? (e.g. a woman-woman, or man-man talk)?

Date	What I did	How it went



## 5. 'I want you to know that these things are important'

### Have you thought about these things?

- Decisions are often made because of feelings. Have you talked with the person about how they feel?
- Do you know what their family and cultural values are likely to be?
- Sometimes it's not the right moment for a decision to be made. Can you wait until the right time?
- People make decisions best when they are relaxed and comfortable. Can you help find a place and a situation which is relaxing?
- People need to feel confident. Think about things you can do, to help them feel more confident.

Date	What I did	How it went

## References

- Antaki, C., Finlay, W.M.L. & Walton, C. (2007). Identity issues in proposing activities to persons with a learning disability. *Discourse and Society*, 18, 393-410
- British Medical Association and the Law Society (1995) *Assessment of mental capacity: Guidance for doctors and lawyers*. London, BMA.
- Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice*.
- Department of Health (2008) *Valuing People Now*. London: Department of Health.
- Felce, D. and Emerson, E. (2001). Living with support in a home in the community: Predictors of behavioral development and household and community activity. *Mental Retardation and Developmental Disabilities Research Reviews* 7(2): 75-83.
- Finlay, W.M.L, Antaki, C., Walton, C. & Stribling, P. (2008) The dilemma for staff in 'playing a game' with a person with profound intellectual disabilities: empowerment, inclusions and choice in interactional practice. *Sociology of Health and Illness*, 30 (4), 531-549
- Harris, J (2003) Time to make up your mind: why choosing is difficult. *British Journal of Learning Disabilities*, 31: 3-8.
- Hatton, C., Craig, J., Wigham, S. and Gudgeon, E. (2006) *Developing measures of job performance for housing support staff working with people with learning disabilities: Final Report*. Lancaster: Institute for Health Research.
- Jenkinson, J. (1993) Who Shall Decide? The relevance of theory and research to decision-making by people with an intellectual disability. *Disability, Handicap and Society*, 8 (4): 361 – 375
- Mansell, J., Elliott, T., Beadle-Brown, J., Ashman, B. and Macdonald, S. (2002) Engagement in meaningful activity and 'active support' of people with intellectual disabilities in residential care. *Research in Developmental Disabilities* 23: 342-352.
- Mansell J. and Beadle-Brown J. 2004. Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities* 17: 1-9.
- Mental Capacity Act 2005 London, The Stationery Office.
- Mental Health Foundation (ongoing) *Preparation and Implementation of the Mental Capacity Act in Statutory and Non-Statutory services in England and Wales*

Rapley, M. (2004) *The Social Construction of Intellectual Disability*. Cambridge: Cambridge University Press.

Robertson, J., Emerson, E., Hatton, C., Gregory, N., Kessissoglou, S., Hallam, A. and Noonan Walsh, P. (2001) Environmental opportunities and supports for exercising self-determination in community-based residential settings. *Research in Developmental Disabilities* 22: 487-502

Simpson, M. (1999) Bodies, brains and behaviour: the return of the three stooges in learning disability. Chapter 15, pp 136-148 in M. Corker and S. French (eds) *Disability Discourse*. Buckingham: Open University Press.

Suto, Clare I. and Holland, T. (2002) Substitute financial decision-making in England and Wales: a study of the Court of Protection. *The Journal of Social Welfare & Family Law*, 24, 37-54.

Walmsley, J. and Johnson, K. (2003) *Inclusive Research with people with learning disabilities*. London: Jessica Kingsley.

Williams, V. and Holman, A. (2006) Direct payments and autonomy: issues for people with learning difficulties. Chapter 5: pp 65-78 in J. Leece and J. Bornat (eds) *Developments in Direct Payments*. Bristol: The Policy Press

Williams, V., Ponting, L., Ford, K. and Rudge, P. (2007a) *Skills for Support: A New Kind of Support*. ([www.bristol.ac.uk/norahfry](http://www.bristol.ac.uk/norahfry))

Williams, V. & Battleday, S. (2007b) *Where do you want to go next? Critical factors in care planning for people with learning disabilities, and their financial implications*. South West Regional Centre for Excellence. Report available from [www.bristol.ac.uk/norahfry](http://www.bristol.ac.uk/norahfry)

Wong, J.G., Clare, I., Gunn, M. and Holland, A. (1999) Capacity to make health care decisions: its importance in clinical practice. *Psychological medicine*, 29, 437-46.

Case law: Re "A" [2000] 1 FLR 549, [2000] 1 FCR 193. (U.K.)  
[http://www.cirp.org/library/legal/Re\\_A2000/](http://www.cirp.org/library/legal/Re_A2000/)

## Appendix A

### Workshop agenda

#### Listen to what I want

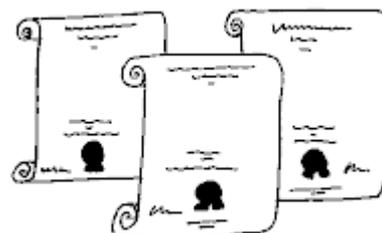
##### 1. Lisa Introductions to people and to the project



##### 2. Warm up What decisions have we made in the last few days?



##### 3. Marcus: what is the Mental Capacity Act?



#### 4. Lisa to lead – How do people get support in making decisions?



#### Break



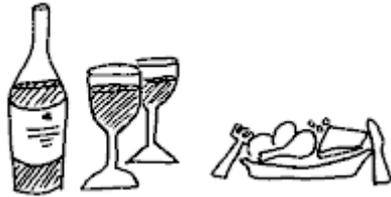
#### 5. Telling our stories about the decisions in our lives

Split into 1-1 groups

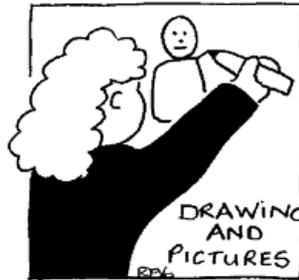




## Lunch



## 6. Finishing off our stories



## 7. Good ways of making decisions: what have we learnt?

**Thank you for coming! We can give you a £10 voucher to say 'thank you'. You can decide what sort of voucher you'd like.**

## Appendix B

### Final action workshop agenda Listen to what I want

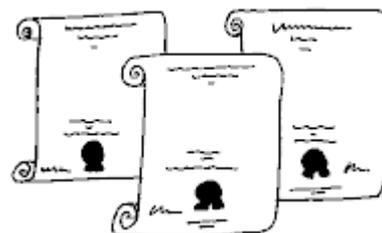
#### 1. Lisa Introductions to people and to the project



#### 2. Warm up Choices game



#### 3. Marcus: what is the Mental Capacity Act?





## 6. Case studies: in groups



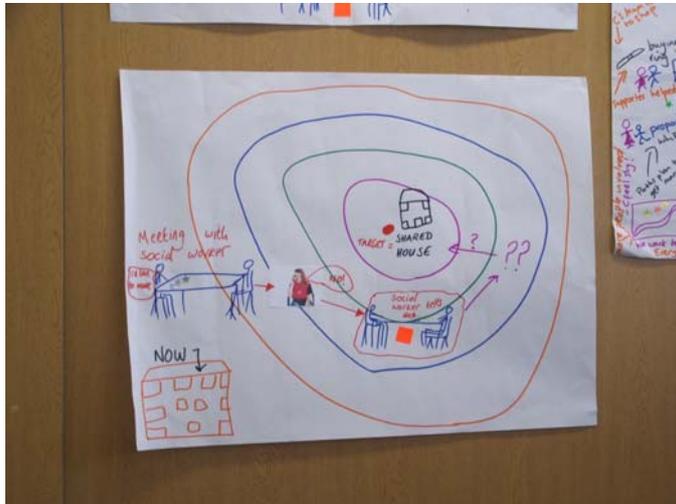
6. **Feedback and discussion: this is the 'action' bit. We want to know what else to add to our model and our checklist!**

**Thank you very much for coming! We will let you have a copy of the report and the summary.**

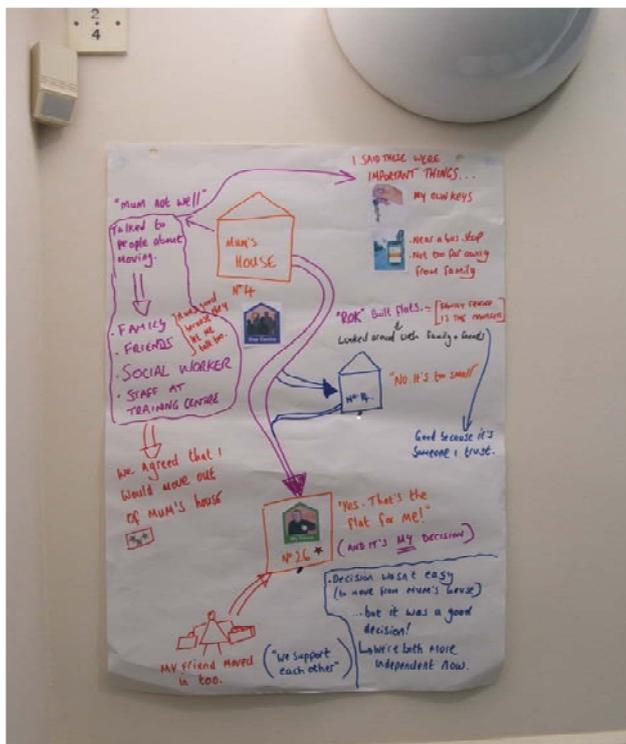
**Please make sure we have got your contact details.**

## Appendix C

### Examples of decision-making maps



- The target is clear here
- Decisions often involve meetings
- Feeling in control with your social worker



- Decisions are often about feelings
- The time needs to be right
- Getting good support is important
- We need people we can trust