



Money, Rights and Risks

A scoping review of financial issues for people with learning disabilities in the UK

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Further information

This report and a summary version are available in print, pdf and Word from Friends Provident Foundation, Pixham End, Dorking, Surrey, RH4 1QA (foundation.enquiries@friendsprovident.co.uk and www.friendsprovidentfoundation.org).

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- Money Advice Trust, London
- Cardiff and the Vale Parents' Federation, Cardiff

Executive summary

This report reviews financial issues for people with learning disabilities and their families, across the UK. It draws on a literature search, focus groups and interviews. There is also some reflection about the issues for financial providers, based on a small sample of interviews, and the report ends with recommendations for practice and further research.

First, here are some views of people with learning disabilities:

I'm too scared to go up to the counter – I'm scared. Initially, to set up the account with all the paperwork, I needed help to go through it.

50p was just about enough to get me a Mars Bar or something, or a drink. But not enough to run me a flat like I have got now.

We went down to the building society to cancel my Visa card, tore it up and chucked it in the dustbin. And got an ordinary savings account card, where I can't use Visa.

It is more often that I keep spending and spending, than I am saving.

I just think and go: 'Do I really need it?'

Issues for people with learning disabilities

- People with learning disabilities are all very different from each other. Some people are very dependent, and others live by themselves with support. About 25 per cent use specialized learning disability services. The 35 people who took part in this review all used some type of support service.
- In our review, there were many people who did not understand money. At one end of the spectrum, 40 per cent were not sure about coins and notes, and their value. However, as many as 86 per cent were confused over benefits, income and expenditure.
- Money was a difficult topic for people with learning disabilities. They often said they were frightened of money, and that they didn't understand bills or budgeting.
- 74 per cent of the people in this review relied on carers and parents to control their finances. They felt they needed this support, but also found it frustrating not to be in control.
- People with learning disabilities said that banks and other financial institutions were difficult for them. Only 51 per cent had a bank account in their own name. This was often because of inaccessible information and procedures.
- People with learning disabilities needed to learn about using money responsibly. Carers

- said that people learn best in small steps, and in real situations. Some people had good opportunities for learning, at home with their parents, or on college courses.
- Only about 10 per cent of people with learning disabilities had paid work, and many were worried about losing their benefits entitlement if they took part-time jobs. Clear information about benefits was hard to come by.
 - Many people with learning disabilities had low incomes, coupled with high outgoings. Literature suggests that they have about £200 per week less than is necessary to enjoy an acceptable quality of life. This affected both themselves and their whole family.
 - Many people with learning disabilities were only given what amounted to pocket money. They tended to spend their money on small personal items, holidays, snacks or sweets. It was hard for them to learn about budgeting for bills, food shopping or major expenditures.
 - People with learning disabilities could be very vulnerable to offers of loans or other financial products. They often did not understand that they had to be careful about loan sharks or cold calling. They were also worried about credit arrangements, overcharging and debt.
 - Problems and worries relating to money could result in mental distress, and this had happened for at least two out of the ten people in supported living.

Issues for carers and families of people with learning disabilities

- It was hard to separate out ‘financial’ issues from all the other issues of supporting a person with learning disabilities in the family home. Families were often engaged in what they perceived as battles to obtain appropriate supports for their learning disabled member.
- Carers said that the whole family was often interdependent financially. None of the primary carers had had the chance to pursue a career, because of their caring responsibilities.
- Carers’ allowance and the right to pension credits were both appreciated, but represented only a small recompense for many years of skilled work in supporting a person with learning disabilities.
- Parents felt responsible for the financial security of their son or daughter with learning disabilities. They were confused and frustrated when their child reached the age of 18 and they ceased to have parental rights.
- Family carers could support their son or daughter to learn about handling money.
- Carers and family members suffered from a lack of clear information about matters such as capacity, financial rights, benefits, and wills.
- In some instances there were examples of sensitive paid support staff, who helped people with learning disabilities on a one-to-one basis to gain control over their budget in a responsible way.
- Support workers and carers need training in financial matters, in order to teach and support people with learning disabilities.
- Families of direct payments¹ users with learning disabilities felt positively about the opportunities offered. However, they needed better advice, support and understanding from banks and from social services.

¹ A direct payment from social services is money given to a service user, in lieu of providing services. Since 1996, social services departments have been empowered to provide direct payments, and since 2001 they have been instructed to always offer the choice of a direct payment. The service user can decide whether or not to take up a direct payment.

Financial providers and support services

- Despite active targeting of people from particular socially excluded groups, the services taking part in this review did not specifically provide a service to people with learning disabilities.
- Financial support services were aware of many societal problems, including a growing ‘debt culture’, the difficulty of understanding debit, credit and interest rates, and the need to learn financial capability.
- Customers of these services generally got a personalized service.
- The Citizens’ Advice Bureau (CAB) we interviewed was moving its attention to education; through schools programmes and elsewhere, CAB staff were promoting the learning of basic financial capability.
- People with learning disabilities got financial support either from parents and carers, or from paid support staff. Some also accessed courses about money skills in FE colleges or day centres.
- Banks were seen by people with learning disabilities as confusing and unsupportive. People described many self-help strategies they had developed for saving money and for budgeting.

Key recommendations for financial services

- Services such as advice shops and CAB could be funded to work specifically with people with learning disabilities. Action research alongside these initiatives would also be useful. The barriers between ‘specialist’ and ‘generic’ financial supports need to be broken down.
- People with learning disabilities need better planned, intensive financial support packages when they plan to move into independent living. They also need safeguards, to ensure minimal financial risk.
- Family carers and support staff need direct advice and information, especially on the topics of benefits, income maximization, and wills. They also need training, so that they can offer financial support.
- Banks and other financial services need to provide accessible information that can be used by people with learning disabilities.

Further research

Further research should be undertaken on the financial support strategies needed by carers and support staff. It would be useful to conduct a larger scale analysis of people with learning disabilities moving into independent living.

Research could also provide more qualitative understanding of the ways in which financial support services operate, and how these services could be extended to include people with learning disabilities.



Chapter 1

Introduction and background literature

SUMMARY

Low income is a significant issue for people with learning disabilities. Very few earn much money, and they experience additional costs due to their disability. They also lack financial autonomy and access to their own money, through carers and families monitoring and managing their income.

The introduction of direct payments for social services support signals the Government's recognition that direct access to money can offer increased autonomy and control, and although uptake has been low there is evidence that formal support can increase it.

There is evidence that people with learning disabilities find access to banking services difficult, though some providers are attempting to address the issues. Barriers to banking are extremely significant, in view of the switch to direct credit transfer of benefits.

Overview

This is a report of a scoping study carried out by the Norah Fry Research Centre at the University of Bristol, for Friends Provident Foundation, between January 2005 and December 2006. It is about financial issues for people with learning disabilities and their families, and includes a brief overview of some of the services offered by financial providers in relation to people with learning disabilities.

'Money comes into everything', as one of the family members said in our focus groups. For people with learning disabilities it is a key issue throughout their lives, and underpins every other aspect of their independence, choice and control. However, as will be seen below, it is an under-researched and often taken-for-granted aspect of the lives of people with learning disabilities. That is why this small scoping study is important, and we hope that it will lead to useful outcomes.

Definitions and prevalence

About 1 in 50 people living in England has a learning disability, but only about 25 per cent of those use specialized learning disability services (Emerson et al. 2005). There are no reliable or exact statistics for the prevalence of people with learning disabilities, but the Foundation for People with Learning Disabilities (FPLD 2006) estimates that:

- 580,000–1,750,000 people in the UK have mild learning disabilities;
- 230,000–350,000 people have severe learning disabilities.

We know that at least 1 in 200 people has an autistic spectrum disorder, and many of these will have an associated learning disability and will be included in the estimates above.

What is a learning disability? According to Department of Health (2001) definitions, people with learning disabilities have:

- a significantly reduced ability to understand new or complex information and to learn new skills;
- a reduced ability to cope independently;
- these started before adulthood, and have a lasting effect on development.

Not all the population of people with learning disabilities will be ‘service users’; depending on their social functioning and their circumstances, many may be living in the community without particular support. However, at the other end of the scale, this population includes people with profound and complex needs, who may need support in basic communication and care, and in every aspect of everyday life. All these people, at various levels, will have needs for accessible communication and information (Rodgers et al. 2004). In the past decade, there have been increasing attempts to provide information in ways that people with learning disabilities can understand, and indeed the right to accessible information is enshrined both in the UK Human Rights Act (1999) and in the Disability Discrimination Act (1995).

People with learning disabilities live in various situations, including residential care, group living and in the parental home. Recent government policy and strategy (Department of Health 2001; Prime Minister’s Strategy Unit 2005) has promoted independent living, control and choice, and people are moving into situations such as supported living, independent living, home ownership or part-ownership. However, as *Valuing People* (Department of Health 2001) stated, and as was confirmed by a national survey in 2005 (Emerson et al. 2005), people with learning disabilities are ‘amongst the most socially excluded and vulnerable groups in Britain today’ (Department of Health 2001: 1).

Financial issues for people with learning disabilities

In relation to financial matters, a major problem for this population is low income. This was underlined by Bewley’s (1997) survey, which found that people with learning disabilities were often denied rights of access to their own money, whether they were living on benefits or were dealing with a larger sum of money, such as an inheritance. Emerson et al. (2005), in the largest recent survey of people with learning disabilities in England, took the range of items

Table 1

Percentage of people who want, but cannot afford, items – Emerson et al.'s 2005 survey of people with learning disabilities, compared with Gordon et al.'s 2000 survey.

| | <i>Heating (%)</i> | <i>New clothes (%)</i> | <i>Going out (%)</i> | <i>Hobby (%)</i> | <i>Going to pub (%)</i> | <i>Holiday (%)</i> |
|--|--------------------|------------------------|----------------------|------------------|-------------------------|--------------------|
| <i>Poverty and Social Exclusion survey</i> | 3 | 5 | 15 | 7 | 10 | 17 |
| People with learning disabilities | 4 | 16 | 16 | 17 | 18 | 26 |

Note: Adapted from Emerson et al. 2005, showing comparable data from the two large-scale national surveys.

used in the *Poverty and Social Exclusion* survey (Gordon et al. 2000) to discover how many people could not afford the things in their lives that most adults would want. The results were significant. People with learning disabilities were far less likely to be able to afford these things than the people who took part in the *Poverty and Social Exclusion* survey (Table 1).

One significant factor that causes poverty is the additional cost that any disability entails, including learning disability. Smith et al. (2004) set out detailed information about the additional costs for disabled people. They conclude that the weekly income of disabled people who are solely dependent on benefits is about £200 per week less than the amount required to ensure an acceptable, equitable quality of life. This picture is supported by the Disability Rights Commission submission to the Equalities Review (2005). Although it is well known that poverty and additional costs will affect people with learning disabilities, since the 1990s social services cuts have resulted in people increasingly having to contribute towards the costs of their own care and support (Eaton 1995).

With new policies of community inclusion (Prime Minister's Strategy Unit 2005; Department of Health 2005), people with learning disabilities are increasingly receiving individualized services – with the expectation that their activities will be located alongside and with other community members and in ordinary community places. However, there are financial implications to community inclusion, as Myers et al. (1998) point out. These could operate as a constraint to using local resources, and as an argument for using segregated resources, or community resources at 'special times', in that they are subsidized.

As was also pointed out by parents and carers in the current study, there are hidden costs to being learning disabled – such as the price of entrance fees, which are often doubled by the fact that people need a supporter or family member to accompany them when going to a leisure centre, a sports match or even to the cinema. There are some schemes in leisure centres where the carer obtains free entrance, and this kind of arrangement could be more widespread.

Very few people with learning disabilities are significant earners. Beyer et al. (2004) found that, at most, one in ten people with learning disabilities who used day services had any kind

of paid work. This estimate was increased to 17 per cent in Emerson et al.'s wider survey (2005). However, all research studies concur that the majority of workers with learning disabilities are still taking up part-time work with a very low number of hours per week, often as few as 5 hours per week. Wistow (2003), in a qualitative study of 30 people in work, discovered some very varied experiences of 'social inclusion' through work, and people with learning disabilities were still very worried about the 'benefits trap', fearing the loss of incapacity-related benefits if they took up a part-time or temporary post. Cole and Williams (2006) found that some areas of the country were supporting people with learning disabilities to find much more substantial jobs, where they would qualify for Access to Work and tax credits. However, it is still hard for many people with learning disabilities to 'make work pay'; their costs of care, support and daily living are simply too high, and so they still often remain trapped on Incapacity Benefit (Ponting et al. 2006).

In addition to general poverty and inability to earn sufficient amounts of money, people with learning disabilities often face problems of lack of financial autonomy. Many studies (Bewley 1997, 1997b; Emerson et al. 2005; Fyson and Ward forthcoming) have underlined the problems around choice and control for people with learning disabilities, in relation to money matters. Bewley found that many people with learning disabilities had carers and parents who often maintained complete control over their finances, and simply allowed them a small sum each week as 'spending money'. People with learning disabilities who took part in Bewley's (1997) survey generally had very little idea of the extent of their own income. This was also true for people who took part in the UK-wide survey of employment for the Department for Work and Pensions (Beyer et al. 2004). Clare et al. (2005), in a study of 30 men and women with mild learning disabilities, found that difficulties in understanding information constituted one of the biggest barriers to financial decision making.

Finally, there is evidence in the literature about situations of exploitation that could amount to financial abuse, which people with learning disabilities face in their everyday lives. Bewley (1997) found evidence of abuse, and this was reiterated by Hassell (1998) with a case study of someone with learning disabilities who was exploited by a solicitor. However, there is little systematic evidence as yet to substantiate the level of financial abuse facing people with learning disabilities.

The combination of lack of income and lack of control often has a particularly negative impact on general mental health, and on social functioning, as Northway (2001) points out. People with learning disabilities still find themselves excluded from many aspects of life that the rest of society takes for granted. Despite the Government's stated commitment to tackle social inequality and exclusion to create an 'opportunity society', people with a learning disability who have high support needs are all too often socially and financially poor – living in the community, but not as part of it (Ward 2004).

Service supports and direct payments

It is now recognized by Government strategy that direct access to money can offer increased autonomy and control. Social services departments are now empowered to give disabled people a direct payment in lieu of services. Disabled people themselves campaigned for the

Community Care (Direct Payments) Act 1996, and although people with learning disabilities have been slow to take up direct payments (Gramlich et al. 2002; Williams 2006), an increasing number of people are now taking advantage of this system. Essentially, a recipient of a direct payment is enabled to be an employer of his or her own support staff, or to organize their support in other ways. This system has given many people with learning disabilities a new-found freedom (Stainton and Boyce 2004; Gramlich et al. 2002) that is changing many lives. However, there are still many barriers.

Despite many positive examples, people with learning disabilities have been relatively slow to take up direct payments. Between September 2002 and 2005, the figures for direct payments users with learning disabilities rose from 741 to 3,803 (CSCI/Healthcare Commission 2006), but people with learning disabilities are still about four times less likely to be in receipt of direct payments as people with physical or sensory impairments (Davey et al. 2006). Disabled people have to be deemed willing (to consent) and able (to manage) their direct payment, in order to receive one, and this provided an initial barrier to the inclusion of people with learning disabilities in direct payments provision (Ryan and Holman 1998; Williams and Holman 2006). These factors seemed by definition to exclude people with learning disabilities. However, support schemes, supply of personal assistants, and family-based independent living trusts have all had a significant impact on the success of direct payments for those people with learning disabilities who do choose them (Luckhurst 2006).

Some of the recommendations to social services departments, from research in direct payments generally, can be applied directly to the learning disability field. These include better systems within social services departments for costing out direct payments packages, but also means for reducing the bureaucracy and paperwork demanded of direct payments users. The research (literature or fieldwork) suggests social work and learning disability teams need better support to learn themselves about the financial side of direct payments, so that people with learning disabilities will be better supported to manage the demands of becoming an employer (Williams, 2006). In general, where financial decision-making capacity is an issue we need to find the balance between respect and autonomy, and protection from abuse and exploitation (Suto et al. 2005a). Suto et al. (2005b) suggest ways to help develop decision-making abilities and maximize choice and independence, by offering basic skills education and by helping people to gain experience of financial decision-making.

Banks and other financial providers

The issue of opening a bank account for a direct payment has highlighted wider problems in accessing banking services for people with learning disabilities (Gramlich et al. 2002), and that theme has been followed up in this review. Many people with learning disabilities live their lives without access to any financial services. Hurcombe (2004) reports that two million people in the UK are not using financial services (people who are mostly not in employment, living on benefits, social housing tenants – including people with learning disabilities).

However, the move to payment of benefits by automatic credit transfer represents a huge change for people with learning disabilities. As Hurcombe (2004) reports, people sometimes get refused a bank account because they cannot prove their identity. Banks sometimes made

their own judgements about a person's ability to manage a bank account. Internet banking has been suggested as an alternative for people with learning disabilities but the Disability Rights Commission has shown that 81 per cent of websites are inaccessible to disabled people. Current levels of financial exclusion undermine Government attempts to meet social and welfare priorities (Institute for Public Policy Research and CAB 2003). This situation is not unique to the UK. Australian research (Hayes et al. 2003) indicates that financial service providers do not fully embrace their community obligations to 'low income customers and citizens'. These authors found that there were mediocre levels of satisfaction and a perception by people with learning disabilities, and their carers, that banks were discriminatory and unfair, that they made errors and were not accessible.

Livingstone (2007) reports on an in-depth analysis of banking, in relation to people with learning disabilities, and suggests practical strategies for improving the financial autonomy of people with learning disabilities, whilst also respecting their safety. In our literature search, we found some examples of banking services that had made particular efforts to include people with learning disabilities and to explain banking procedures (Barclays 2005). MENCAP (1999) also produced a fact sheet called 'You and Your Bank', and there are a number of other attempts to explain banking to a variety of customers in accessible ways (for example the Money Matters website – www.moneymatterstome.co.uk). It suffices to say that the evidence base for the use of financial services by people with learning disabilities is very thin. At a time when people with learning disabilities are being encouraged by national and local policies to use ordinary, community-based services, the issue of the use of financial institutions is a major cause for concern and for further enquiry.



Chapter 2

Methods, and characteristics of people in the study

SUMMARY

This review drew on recent and ongoing research, three focus groups for people with learning disabilities, two focus groups for carers and ten individual interviews. The range of people interviewed for this study was very wide, from people with high levels of dependency to those living independently with support.

This review drew on a wide range of recent and ongoing research in the field of learning disability, as well as three focus groups for people with learning disabilities (N=25) in different areas of the country and ten individual interviews. Eight of these ten interviews included a support worker, who sometimes intervened or clarified an answer during the interview. There were also two focus groups for carers (N=11), and one of these groups included two professional support workers. All these interviews and focus groups were tape recorded and transcribed, before a thematic analysis was carried out. This was facilitated by use of the computer package MaxQDA. Also, discussion was held with two family members of people with learning disabilities who received direct payments. Additionally, we report here on material from research carried out by the Norah Fry Research Centre. In this report, we use data from the projects listed in Table 2, which also gives the number codes by which we will refer to them.

The 35 people with learning disabilities who took part in the groups and interviews had a wide range of levels of ability, independence and understanding of money. However, they all shared a 'vulnerability' about money issues, expressed by one parent in this way:

And the thing is, my daughter, anybody could go to my daughter and say, can you write your name on there, she'd sign it on anything. So they could potentially take her money.

The range of people included in the sample for this study was very wide, and included people with high levels of dependency. For instance, the people in one of the focus groups (N=6) were all older, lived in supported situations, and had very limited experience of independence. One of the young people whose parents we spoke with in a focus group also had multiple and complex needs. These people tended not to have access to their own money, and were dependent on carers, family members and other supporters. By contrast, the ten people who

Table 2
Research projects at the Norah Fry Research Centre

| <i>Project number and name</i> | <i>Subject matter</i> |
|--|--|
| 1 <i>Parents with Learning Disabilities: Getting good support</i> (Tarleton et al. 2006) | People who may have moderate or mild learning disabilities, and have children of their own. |
| 2 <i>Skills for Support</i> (Williams et al. ongoing research) | People who use direct payments, or one-to-one support. Many are articulate, and have a good idea of what it means to 'be in control'. However, the sample includes people with multiple and profound needs, and one person with severe, challenging behaviour. |
| 3 <i>Transition: 'Bridging the divide'</i> (Heslop et al. 2002) | Young people with learning disabilities aged 14–19, and their parents. |
| 4 <i>Supported Living</i> (Fyson and Ward forthcoming) | People with learning disabilities who have used the Supported Living Fund, and have moved into accommodation where they can live more independently. |

were interviewed on a one-to-one basis lived in 'supported living' situations, where people live independently with regular input from support staff. These people (N=10) were able to express themselves verbally with more fluency, and talked about a number of matters relating to budgeting, saving and banking. These are people who may not have a 'visible' impairment, and who may not even define themselves as having a learning disability.

The much larger groups of people represented through our ongoing research projects comprise an even wider spectrum of levels of independence. People with learning disabilities are a very mixed group. It is hard to make instant accurate judgements about the level of support a particular person might need, and this is very relevant for financial providers who may be unsure about how much support an individual needs. One carer put it like this:

With my daughter – she has language and she can speak, like you say processing, understanding; whether it's appropriate is not always in it. She is very trusting – for her, everybody is a nice person.

People who are trusting, who may not seem to be 'disabled', but who nevertheless have difficulties in understanding information, are particularly vulnerable.

In this report, we assume that, whatever their level of ability, everyone has a right to have access to good financial advice, and to appropriate learning opportunities relating to money. As one provider said:

Even if people don't get to the stage of managing their finances, they can still understand that other people may manage it for them, and they can [understand the difference between] 'wants' and 'needs'.

Chapter 3

Findings: Financial issues for people with learning disabilities

SUMMARY

Many people with learning disabilities interviewed for this study did not understand the concept of money, nor where it came from. Many also lacked control over their money, and were instead given small amounts of pocket money. Their understanding of spending therefore related to the treats they spent this money on – typically CDs, magazines and DVDs – rather than essential expenditure on bills, rent and food.

People with learning disabilities found it hard to understand banking processes. They often relied on carers and family members to assist them. They also had few opportunities to improve their financial knowledge through education, although some parents and carers focused on helping those in their care to use money more regularly and responsibly.

Personal income was not enough to live on easily. Some people had taken on credit they did not understand, and could not afford.

Overall, many people with learning disabilities found the issue of money a very stressful subject.

Understanding the value of money

Many of the people in our study only had a vague idea about the actual amounts of money that made up their income and expenditure. The spectrum of understanding ranged from one person who could not recognize a pound coin, to others who knew that ‘money is for spending’, and that ‘if you want something in the shops, you’ve got to pay for it’. Fourteen people (40 per cent) had problems understanding the value of money, or understanding coins and notes. However, 30 people in this review had further problems with bills, budgeting or expenditure (86 per cent).

Even amongst those who were living independently with support, their understanding of amounts of money was often very inexact:

And how much a week do you spend on average on food shopping?
Roughly around £20. Roughly.

So that leaves you about £80 to spend on what you want?

Let's see, if I take £20 out of [closes eyes] Nationwide, I can...that it is going to leave me with...yes you are right then £80.

£80. OK. And that lets you do all the things you want?

And that has got to last me to the rest of the week.

And does it?

No. No [looks at supporter], unfortunately because I keep hammering my £100 a week, so coming towards the end of the week I am skint.

For many people their understanding of where their money came from was also limited, and this seemed to be linked to parental or carer control over finances. People with learning disabilities frequently mentioned that money came from their family, and they felt different (or 'left out') because siblings and other family members could access their own money whereas they could not.

As far as the value of money was concerned, supporters and carers often felt that the person with learning disabilities had very limited concepts. One parent said:

There's no way he could go and shop. I mean, if he had a ten pound note and they only gave him change for a five pound note, he wouldn't have any idea.

A support worker with one of the interviewees also expressed concerns over his lack of understanding:

He has a lot of input from others when it comes to the actual control of his budget because he is not fully aware of the value of money. So we do keep a keen eye on him. That's why at the moment he is on a controlled budget.

Such concerns are clearly very common, and lead to a situation where other people (supporters, family members, carers) effectively take over control of a person's money in order to help them with budgeting. This control can take various forms, as we will see below.

Control over money

Bewley (1997) found that there were many people with learning disabilities who did not have any control over their finances. This was also a very strong theme in our data, and the following conversation between Maggie (assumed name) and her supporter was typical:

Maggie: I get it every bloody week. Pocket money.

Supporter: Who gives you the money for your fish and chips?

Maggie: Sarah does...She says 'What's this – go and get your fish and chips.' 'Alright', I says, 'I'll go up for you.'

Heslop et al. (2002: Project 3) emphasized how important financial independence is as a marker of adulthood, as young people reach the age of 18. However, this is very seldom achieved by young people with learning disabilities. Few of the young people interviewed in Project 3 managed their own money. Some parents said that the young person was ‘baffled’ by money, that they ‘hadn’t got a clue’ or ‘couldn’t handle it’, couldn’t recognize its worth, or might be vulnerable to exploitation. Just two of the young people mentioned that they used their own bank account. Others spoke of allowances, pocket money or of having to ask someone in order to be able to buy something.

Twenty-six of our 35 respondents (74 per cent) said that their parents or support workers controlled their money for them. Some of the respondents in the current survey were aware that their parents or carers kept back money from their allowance, and sorted out their affairs for them. Others merely focused on the ‘pocket money’ they got each week, generally in the order of £20. One person said that her mother took her money from her benefits, paid it into her own account, and then drew it out for her when she asked for something. While some people might welcome the safety net, this is a very tight level of control, and for many it meant that they seldom had a chance to think about how much they could afford for any of the things they wanted or needed. In effect, this meant that many people were restricted from making the choices they wanted to about how to spend their money:

I’d like to go out before Christmas, by myself, but my carer won’t let me go out. I’ve got a friend from the Gateway Club, and I want to go out with her and have dinner with her. But my carer doesn’t want me to.

It was recognized, both by people with learning disabilities and by carers’ groups, that there are some people who may not be capable of understanding or dealing with money at all. As one of the people with learning disabilities in the current study expressed it, people may need a ‘guardian’ to look after their money. However, this does not mean that they cannot have choice in their lives, and take small steps in recognizing and spending money; as one person with learning disabilities said, ‘If we want to go out somewhere with support, as long as the bills are paid, we should be able to do that.’

What did people think of this situation? For people with learning disabilities, it seemed to make the whole topic of money a difficult and obscure subject. Money became, in effect, a symbol for someone else taking responsibility over one’s life. Several of the people in the older people’s focus group accepted this situation as part of their lives; others, however, felt that things could be done differently.

Some people are getting more control over their lives through ‘person-centred planning’, where the person with learning disabilities is supported to work out their own goals:

I’d like to give you a good example, about when the person does a plan – it doesn’t always work immediately, because it’s still in the early days. But I’d like to give you an example of when it does work. Before, my benefits used to go into my bank account, and they used to give me so much money each week. But now, with help, I’ve got control of all of it.

The people who were interviewed, and lived more independently, mostly had supporters who gave them sensitive support about financial matters. In Project 2 people also had good support with budgeting, which enabled them to feel in control. In general, people with learning disabilities wanted to learn more about their money, and were anxious to take more control. However, we know from emerging findings about supported living (Project 4) that people with learning disabilities who live more independently can still find themselves under very tight budgetary control.

Carers and parents in the current study felt that they had to be totally responsible for their son or daughter's well-being, but were aware that once their offspring reached adulthood they would not be able to access bank account details. The parents we spoke with felt this was problematic, particularly with young people who had moderate learning disabilities. This parent had fought to become an 'appointee'² for her son:

I'm an appointee, but that took years to do that, and I got to a point where I'd go through to an office trying to get Working Tax Allowance sorted out and, 'Oh, I'm sorry Mrs – I can't speak to you, I have to speak to your son.' I said, 'No, you can't.' 'Well are you the appointee?' 'Yes I am.' 'Well I haven't got you down as an appointee', and I said, 'Well I can assure you I am.'

Easy information and opportunities for learning

One of the biggest barriers for people with learning disabilities is the lack of accessible information about finances, banking and other money matters. People in the focus groups said how hard they found it to understand banks, cheque books, information leaflets from the banks, and forms related to benefits. One person in a focus group said that he left all the 'forms' to his brother. He had only the vaguest understanding of what the 'forms' were for. Others, who lived more independently, still needed support workers to help them with form-filling, with understanding banking procedures, and with actually using a bank. One person said:

I'm too scared to go up to the counter – I'm scared. Initially, to set up the account with all the paperwork, I needed help to go through it.

If information were provided in better ways, there are many people with learning disabilities who could understand financial paperwork. One man in Project 2 had created his own budget/shopping sheet with large print and pictures, and his support worker simply had to refer him to it, in order to plan the weekly budget. As we will explore in Chapter 4 below, some financial providers are making efforts to provide information in ways that are easier to understand, and this is a main area for future development.

In the focus groups, we also asked people specifically about opportunities they may have had to learn about money skills. Several people spoke about college courses. One person said:

² An appointee is someone chosen by a person with limited capacity, to help them manage their finances, and act on their behalf in financial matters. An appointee is registered with the DWP.

Well, I've been to college about a year. I don't know how many years. And when I started, I did money skills before...I done it four years, money skills. It's like that. I goes out on a trip to town every Monday when I'm at college. I spend money. We go in a café on the way back home, for a drink. We do our shopping up there. We buy anything – we go into Sainsbury's.

Many others also identified the opportunities they had had as children, and as young people, of learning from their parents. One person said, for instance, that she had watched her mum paying bills: 'As soon as a bill came in, she went and paid it.' This had been a helpful form of role-modelling. In most cases, the practical, active aspect of learning was paramount. Good learning opportunities for people with learning disabilities involve practical, concrete skills. It is not enough to sit down and calculate budgets on paper. People need money in their pockets, and the opportunity to go and buy something 'for real'.

However, this opportunity was denied to them surprisingly often. In one of the focus groups, four of the six people said that they were not allowed to hand over money in a shop. Instead, the person with them (a carer or a family member) would be more likely to pay for them.

In the *Skills for Support* project (Project 2) there was interesting evidence of how disempowering this situation could be for someone with a learning disability. In this project, videos were made of support workers interacting with people with learning disabilities, and in one of these videos we see a support worker and a man with learning disabilities going to a leisure centre to get a new leisure card. Throughout the encounter with the leisure centre manager the man with learning disabilities is completely left out of the conversation, as the support worker has the cash, the forms and the information necessary for the transaction in his own hands. A few minutes later, however, the same pair go into the pub. In this case, the man with learning disabilities gets out his own money to pay for drinks, and the barmaid deals directly with him.

In the current focus groups, two carers discussed in detail the opportunities their sons and daughters had had in school to learn practical money skills, and one parent also explained exactly how she had allowed her daughter progressively to have access to larger amounts of money:

It's a slow process; you do it in stages like we've done, the money comes in and then we sort it out and then eventually, hopefully, then she will take control and I will say to her: Right, this is, you have control now. This is how much housekeeping you need to pay and whatever's left, and bills, and then whatever's left is yours and then you must decide where you want to put it.

Another parent said that her daughter now paid her own gym fee, and was looking forward to the 'next stage' when she would have her own bank card. It is through continual practice that people were able to learn. In one of the focus groups for people with learning disabilities, the support worker said that she regularly supported people to go to the shops. 'I give you all your own money, and you all pay for yourselves. And I help you if you need it.'

However, bigger purchases such as clothes and food shopping may still be done without any direct control by people with learning disabilities. The reason seems to be that many people only have access to pocket money, and so will inevitably get used to spending money on leisure, hobbies or personal items. They get used to only having any money to spend on ‘extras’ or personal pleasures – such as holidays or presents. When they do eventually have control over their own money, it is then very hard for them. They simply want to buy more and more DVDs, magazines or chocolates. One interviewee expressed this as going straight from buying a ‘Mars Bar’ to ‘running a flat’:

50p was just about enough to get me a Mars Bar or something, or a drink. But not enough to run a flat like I have got now.

Pocket money is a good start for everyone, but in order to learn about higher expenditure it is essential that people are allowed to move on and have access to other elements of their money.

The parents who came to focus groups were well aware that they needed to ensure their young people learnt about budgeting, and about the fact that ‘money doesn’t grow on trees’. Budgeting was also identified as a major item in getting good support for parents with learning disabilities (Project 1). Some people in supported living arrangements were often getting intense budgeting support, to enable them to know exactly how much money they can spend on any one occasion. This support was often given directly by one-to-one support workers, and one person with learning disabilities described what it was like to learn how to budget for himself:

When I was 16 or 17, I had to be told about my responsibilities. When I was in lodgings, they would teach me about where my money goes. I need teaching, how to look after my own self, and how to look after my own money. Sometimes people do need a lot of support, like in this place. I know myself – I know quite a lot of people. A lot of people need lots and lots of support.

The kind of learning described here is very much what providers felt should be offered throughout the education system, as we will see below. One parent also said:

It would be nice if we could see this all through the education system, that everybody’s taught how to manage with finances and things...It’s difficult for us to keep up with them, let alone the children.

However, it is not clear how people with learning disabilities are being included in school-based learning about financial matters. Because their learning is bound to be slower, and to carry on for a longer period of time, it will be essential to continue planning for financial education in colleges, in independent living and in continuing education throughout life.

Income

As noted in the introduction to this report, a major problem for people with learning disabilities is low income. The reason that budgeting is so important for many people is not

only their lack of skills and understanding; it is also the fact that they are on an extremely tight budget. One of the projects on which we were able to draw (Project 3) was a national survey of young people with learning disabilities at the transition stage. That work (Heslop et al. 2002) emphasized how difficult it was for families to get any advice about benefits entitlements at the transition stage. Project 4, which was about people who move into 'supported living', reports on the fact that people with *lower* support needs (in 'supported living') often have lower expendable income than those with higher support needs living in residential care.

In our interviews and focus groups, people were asked if their income allowed them to do the things they wanted to do. Exchanges like the following were very common, and of course reflect what is true for almost everyone:

This money you get – does it allow for you to do everything you want to do?

No.

It does sometimes stop you from doing things?

Well...I have to be careful over budget.

Only one or two of the people we spoke with in this study had any form of paid employment, reflecting quite accurately the proportion of people with learning disabilities who have paid work (see Beyer et al. 2004). However, many of our respondents did voluntary work, and some were even paid small amounts of money as a 'token gesture' for work they did. People in the focus groups in general did not link employment with income, but spoke instead of the vague hope of 'getting rich'. Their main income was perceived as their benefits cheque. One of the interviewees, for instance, had a waitressing job. She was paid in cash for that job, and also had benefits that went directly into her bank account. When asked what was the most important to her, she said, 'The money in my bank account.' The people who took part in this study nearly all echoed the familiar worries about work and benefits, and were unwilling to undertake paid work, or anxious about going for it, in case their benefits were affected.

The majority of people in focus groups and interviews relied primarily on benefits to survive. Again, however, their understanding of what benefits they were on was often very vague. Most of the people interviewed in supported living could eventually remember the names of benefits they received, but they often did this with the help of their support workers. One person referred to his benefits as 'post office allowance', and several went into complicated explanations of how they had been misinformed, or had to appeal in order to get certain benefits. Supporters and carers also had problems negotiating the benefits system, as illustrated in this story by one parent:

We've tried really, really hard to get benefit, in actual fact we tried to get Disability Living Allowance and I'm off to a tribunal with her at the end of next October. She applied for that in May, end of October – and I spoke to the Trust yesterday and the lady there said she didn't think we'd get anything because she's an able person in their opinion, she can put, she can put food in the microwave so she can cook, she can walk to work, so we don't have a leg to stand on. I think she can

apply, now I've found out, for Income Support, but I understood that if you're under 25 and didn't have any other benefits, then they couldn't apply for that as well.

Lack of understanding and complications regarding benefits were not the only problems, however. Another basic problem was simply that personal income was not enough to live on easily.

Spending

In the focus groups and interviews, we asked people about what they would like to spend money on, and what their outgoings actually were. Clearly, there are different propensities for spending. One of our interviewees, for instance, said that he budgeted by asking himself 'Do I really need it?' When asked how he discovered this strategy, he simply said it was 'just natural'. Some people are naturally thrifty, and others are naturally big spenders – this is no different for people with learning disabilities.

It was interesting that in the discussions with people with learning disabilities themselves, spending was largely focused on holidays, leisure and what most of us would describe as 'extras'. Most of the people who were living independently knew that they should think about 'food, clothes or stuff for the flat', as one man said. However, these lists were not as interesting to many people as the things they really desired, which included mobile phones, computer games and DVDs. When asked about savings, most people mentioned holidays. Many also enjoyed going out to the pub, or having a meal out in a restaurant or café. In general, people described these things as 'treating themselves':

I like buying clothes, I like buying nice food. I like having my hair done.

Where over-spending had been an issue, this had often occurred in the area of DVDs, mobile phones or CDs. One person in Project 2 had overspent on DVDs when he first moved into his own flat, and his support worker had to give him advice on how to manage his budget so he could afford food.

Younger people with learning disabilities were described by their parents as having dreams of what they wanted, while being unaware of the value:

She does live in cloud cuckoo land, I think, a bit. She looks at the property, she's desperate to become independent and she knows that she wants a lovely loft flat with wooden floors, but doesn't realize how we're going to do it and the value of money.

However, even older people in the focus groups were still very unrealistic about the relative price and value of different kinds of expenditure in their lives. It seemed as if they had only ever taken personal decisions over the 'luxuries' of life, and that other expenditures were perceived therefore as 'boring bills'. Like the young man cited above, they were going straight from a Mars Bar to managing a flat, and this was perhaps too big a step to take.

Alongside this theme of individual spending on personal items, parents and carers were very aware of the expense involved in having a disabled person in the family. None of the people with learning disabilities mentioned this facet of their lives, showing perhaps that they had never actively compared their own way of life with that of a non-disabled person. Extra costs mentioned in the carers' groups included: the costs of going out, when a carer/supporter also had to be paid for; the cost of special transport, including taxis; special foods that their son or daughter needed; and special equipment, including mobility equipment.

Generally, money meant independence for people with learning disabilities. Several people wanted to choose how to spend their money, just as their brothers and sisters did. As they grew into adulthood, and saw their siblings achieving independence, they themselves wanted a similar lifestyle. However, the twin barriers of lack of understanding and lack of income kept them mostly in a world of 'special treats' and extra luxuries, rather than in the world where people earn salaries and buy their own flats.

Problems and abuse

People with learning disabilities face the same potential problems in today's financial world as anyone else. One of the main issues we found in this small survey was direct offers of loans. One carer talked about her daughter, who has moderate learning disabilities:

She had an advertisement from the bank, saying would you like a loan, personally addressed to her, and she has been to the bank once unknown to us to ask about finances. Thank goodness the bank manager must have realized that she had some learning difficulties and didn't take her on the loans/overdraft route.

Blanket assumptions of incapacity on the basis that one suspects someone of having a learning disability are, of course, not legal. Any suspicion of lack of capacity should be fully discussed with those closest to the person concerned, as well as the person themselves (see the new Mental Capacity Act 2005, which comes into force in 2007).

Some of the people who were living independently complained of 'cold calling', both by telephone and at the door, which they found very hard to deal with. This included cold calling to offer 'special deals' on mobile phones, which people with learning disabilities found very hard to understand and to resist. One of the parents with learning disabilities in Project 1 explained how her problems in parenting had been exacerbated by getting involved with a 'loan shark', who kept offering money. She could not read and didn't know what she was signing, nor did she have any idea about interest rates:

I was always stressed out because I was in a load of debt. I had loads and loads of debt...and they used to come to the door and ask me if I wanted loans and all that. Because I couldn't read or write I used to sign it all. I thought, oh I've got money, that'll help towards the kids and all that. Then I got that much in debt I was getting stressed out and everything.

Overall, these problems only hit the people who were living semi-independently, or who had control over their own finances to a certain extent. As one of the financial providers said, door-to-door money lending is a big problem. It is licensed and legal, but people who don't understand the full implications may take on loans with very high interest rates. This was also true for special offer cards in stores, and other forms of credit. The fear of these issues drove many carers to maintain a very strict control over the finances of the person they cared for, as this parent said:

My daughter, anybody could go to her and say: 'Can you write your name on there?' She'd sign it on anything. So they could potentially take her money.

Similarly, arrangements where payments are 'spread out' over time, and even use of credit cards, could cause immense complications for people. Only one person we met had an understanding of what 'interest' was, and why it was charged. The 'small print' was a common issue, even among those who could read and were living quite independently. One man told the following story:

It's complicated because you have interest. And it got to the stage when I had to sell what I was buying, so I could put the money back in, so I could pay it off. I said to them when I bought it – I don't want any insurance on it, or anything like that. And the lady filled out 'Yes' for it, and I didn't want that. And I read through it, but I needed help because it was in very small print, and we only discovered this afterwards, because the rate of interest was quite high. So basically I ended up not having the thing I was paying for.

Credit arrangements were one of the main worries expressed in the focus groups. One person said: 'I wouldn't go there, not really, you get more and more in debt.' People were particularly worried about the real danger of debt and bailiffs, and often felt it was best to avoid any form of credit.

The concept of 'borrowing' was far more likely to be limited to family members or friends of the person with learning disabilities. People spoke about borrowing money from family members, or even from carers, and paying them back. Of course, in most cases this was probably only for small amounts, and without any complicated interest deals. At least three people had also had experiences of family members borrowing from them, and in all these cases they felt they had been exploited. Money was not always returned to them, and one person had needed support from (paid) carers to separate his finances out from his brother's.

Exploitation was a common worry. People with learning disabilities recalled many instances where they had been exploited. The following represents a very common experience:

I've been duped several times, I have. I went in to get a pint yesterday, and he said: 'Give me £4.' But that wasn't fair. I said: 'No.'

The lack of understanding of what might constitute a fair price, together with a lack of expendable income, combine to make people with learning disabilities fearful in general of

being ‘ripped off’. One person felt that the ‘DHSS’ and the water company were ripping him off. Much of this had to do with a lack of easily accessible information. The person who talked about problems with bills felt that he needed to know where exactly his money was going, on a monthly basis. As he did not understand the paperwork that came through with utility bills, he suspected the worst.

Amongst people with learning disabilities living at home, or in more ‘cared for’ situations, one of the greatest worries was robbery. This included being accused of robbery, and worries about others stealing money from them. Several people had vivid stories of occasions on which they had been robbed, and this included experiences in care homes, where other residents had either stolen money or been accused of stealing money. Many had developed strategies for not keeping cash on them, or for keeping money safe. People in one focus group recalled a policeman who had conducted a session on safety in their day centre, and had distributed free money bags to wear underneath clothing. This type of advice seemed to be very well received.

Summary of issues for people with learning disabilities

In general, money is a worrying and stressful subject for many people with learning disabilities. People are being given the message that money is ‘unsafe’ for them to deal with, and this is reinforced by the fact that many people are not allowed access to much of their own money. There seems to be a great deal of surveillance over people’s money, and while this may be necessary to avoid dangers of exploitation it results in people feeling upset that they are not seen as trustworthy. ‘Bills’ in general are a great source of mystification and worry for most of the people living independently, and all of our interviewees needed quite intensive support to manage that aspect of their lives. One person spoke for many when he said:

I don’t understand about the rent, I don’t understand about the electric – nor the water (counting off on his hand). I don’t understand anything like that.

Some people said they were generally ‘scared of spending money’ because of the worries of getting into debt, while others were aware that they would over-spend if they were allowed free access to all their finances. There was a great sense of frustration over not being in control, and confusion over many aspects of finance, coupled with a cautiousness bred of fear (of debt, of robbery, exploitation and over-spending). This situation resulted in some mental health issues for many people, as expressed by this woman:

It has affected my brain basically.

As with other causes of mental distress, this could result in people becoming depressed and inactive, or expressing their frustration through temper and aggression. One man said that he lost his temper, and went ‘ballistic’ when he ran out of money. Another person counter-productively drowned his sorrows in gambling, creating greater problems for himself.

As we have seen in this chapter, there are many aspects to the problems faced by people with learning disabilities, including low income, lack of understanding, complicated information, lack of opportunities for learning, and lack of control over money. These combine to make

the whole subject of income and expenditure a source of great stress, rather than a source of control and satisfaction for most people with learning disabilities. It is interesting to note how similar this picture is, in many respects, to that of other people with low income. As Atkinson et al. (2006) pointed out, people on low income are generally held back from full engagement by lack of financial capability and lack of income, as well as lack of accessible financial support services. In all these respects, people with learning disabilities face the same problems.



Chapter 4

Findings: Families' needs and viewpoints

SUMMARY

Carers interviewed in this study were concerned about the low income received by the family as a whole, largely as a result of their working as unpaid carers for their offspring (in childhood and adulthood) and therefore having to give up their paid careers. This led in some cases to a potential 'benefit trap' for their son or daughter as taking paid work could jeopardize the benefits the family depended on.

Carers need a number of skills and a great deal of knowledge about disabled people's rights, in addition to their caring abilities. They felt that this, and the saving to the state that their care provided, was not being properly recognized by Government.

Family carers of adults with learning disabilities were concerned for the continued financial security of their relative, and this made them very wary of any financial risk. They felt that they were responsible for the income, organization and budgeting of their son's or daughter's money, though they were aware of the importance of enabling their offspring to develop an understanding of money.

Carers and parents are important to people with learning disabilities, particularly as those who live at home mostly pool their finances with their parents' income. As mentioned above, we talked with a range of family carers in this survey – partly through focus groups (11 carers) and also in individual interviews (3). Two of the carers in a focus group were parents of young people, below the age of 18, while all the others were family carers (mainly parents) of older people. In four cases, the adult with learning disabilities had moved on from the family home, and two of the interviews were with carers who were supporting their relative to manage a direct payment and live independently.

Carers often gave more information about the financial situation, worries and issues for their relative with learning disabilities, and that information is included in Chapter 2. However, carers deserve a chapter of their own in this report, since there are many issues that impinge on the family as a whole, and their viewpoints and insights may sometimes be different from those of the people they care for.

Unpaid work as a family carer

Discussions of financial matters with carers were very wide-ranging. For carers, it was often very difficult to separate out matters relating to income and expenditure from other issues relating to their relative's care and support. They were constantly fighting for services and supports that would enable their son or daughter to have an improved life, and this very struggle could have financial implications (in the case of one carer, for example, she was paying for a solicitor to help obtain her daughter's rights).

Carers who took part in Project 3, which was about young people moving into adulthood, said that they had had very little consistent advice about benefits as their son or daughter reached adulthood. Two of the comments from parents were:

It was like [being] in the middle of a maze... You're going round and round and back.

I know I never claimed the Income Support because I didn't know I could until I claimed something else.

For family carers, one of the main financial issues is simply the low income received by the family as a whole. As many carers pointed out, they are 'factored in' to community care; without the support they give to their relative with learning disabilities, the cost of provision from the state would be far higher. Even costs such as utility bills are far higher if someone with learning disabilities is living in the parental home into adulthood. Despite this situation, however, the support provided by family members is not recognized financially, and carers can often find themselves in very disadvantageous positions. This carer spoke for many:

I'm 50 now, she's not even finished school yet. I've had twenty years out of work, who's going to take me? I've had to put my life on hold, and I love her to bits and I've gladly done it. But life is not easy, and you know – I think this government is, for want of a better word, screwing us. We're not even given a minimum wage.

None of the family carers we spoke with had paid work outside the home, although in three cases the main carer was married to a wage-earner (in one case retired). However, there was certainly no possibility for any of these families of having two incomes. One family member at least had to be responsible for supporting their relative with learning disabilities, and this was in effect a full-time job. This had severely affected people's careers. For instance, one parent of a young person in a focus group had been a financial underwriter, and another carer had had a job earning £400 a week in the aircraft industry.

Giving up careers of this nature means a considerable drop not only in earning capacity, but also in work-related pension rights. The recently introduced rights to state pension credits were appreciated, but this appeared almost to be a drop in the ocean in comparison to the situations of many families. One parent expressed the frustration and anxiety this can cause:

The fact that you're so exhausted from caring and the fact that they will come back, who's going to look after her in the holidays if I've got a job? All this – it affects every aspect of your life, it just takes over.

Carers spoke of feeling alienated from the world of work, and particularly when they compared themselves with other parents who had been able to return to work as their children grew up.

The job of being a family carer involves many skills. Clearly, there are personal and care-related aspects of supporting someone with a learning disability. However, other skills included 'going to meetings, chasing, phoning, every day'. Parents had to keep information filed, they had to become experts on matters of law relating to their son's or daughter's rights, and they were in effect doing complicated and demanding jobs as carers at every level. However, this is not recognized financially in any sense. As one parent said:

If I worked as a full-time carer, I would be getting more than £45 a week, plus your stamp.

From the point of view of the family as a whole, this means that there is often a dependence on the benefits brought in by the person with learning disabilities. One parent had had problems because her son worked, and therefore had not qualified for incapacity benefits. His job caused financial problems for the family as a whole:

He was in employment but it wasn't government, it was a private company who took Jack on as a favour to me and him, which I was really pleased about at the time. I thought, 'I'd pay you if you'll give him a life'...and he was in it for 25 years. But because he had that job I had no financial help at all. He started off with £11 a week and it raised, it came up to say £40 a week, but because he wasn't receiving a benefit I was told: 'Oh you can do this, you can do that.' Yes, okay, so I tried for Disability Working Tax, a working tax it was, and I was told: 'No, he doesn't receive a benefit, so no, you can't have it.'

When her son finished working, this mother had considerable difficulty in supporting him to be assessed for Disability Living Allowance. This example, like many others, illustrates the continuing difficulties for people with learning disabilities in gaining a living income. They and their families are often caught in a vicious circle, where parents and carers feel that they have to take maximum control, to ensure safety and to balance the books of the family as a whole.

Financial responsibility for the person with learning disabilities

It is understandable that these family carers will be well aware of the potential problems of any financial risk in the family. Control over the finances of their son or daughter (which has been explored in this report from the point of view of people with learning disabilities) is a natural corollary to the extremely tight financial situation for the family as a whole. Carers of adults with learning disabilities did generally feel that they were responsible for the income, organization and budgeting of their son's or daughter's money.

This did not mean that they were unaware of the potential for learning and development. As reported above, many people with learning disabilities we spoke with had learnt a lot about

budgeting from their parents, and some parents seemed to be particularly skilled educators for their son or daughter. This involved allowing them progressively greater access to money, and making sure that they learnt thoroughly what was expected of them. Certainly, many people with learning disabilities will need that kind of support well into adulthood.

One of the problems parents particularly mentioned was the lack of clarity about their legal position after their child became 18, and officially an adult. At that point, their legal parental rights ceased:

You're not allowed any information about somebody else's account, which is fair, you can understand...but when they haven't got the capacity to do it themselves, somebody has to be there for them.

Some parents had officially become 'deputies' or appointees for their son or daughter, and many others felt that they unofficially had those rights. The new Mental Capacity Act, which comes into force in April 2007, will hopefully clarify this situation somewhat, and ensure that carers and parents do have legal rights to 'have a say' in certain financial and other decisions made by their son or daughter, if their offspring are 'without capacity' in relation to that particular decision. However, it remains to be seen how the Act will be put into practice.

Many parents would have liked greater flexibility, particularly with banks. In order to allow their son or daughter greater independence, they wanted safeguards that overdraft facilities and loans would not be offered. In the final analysis, their main concern was the continued financial security of their relative with learning disabilities, and this made them very wary of any financial risk:

She'll never earn enough money to become independent, we're just trying to work that through now...we're just going to have to make provision for her, because this government won't make provision.

Wills and pension funds were naturally a cause of concern to many carers, as they became older and they wanted to ensure financial security for the future. None of them had had specific advice about this, and solutions or advice were eagerly shared from carer to carer at the focus groups. This is a most important gap, and will be taken up in the recommendations chapter of this report.

Support staff

In this study we did not have the capacity to hold separate interviews with support workers, although several did take part in the individual interviews with people with learning disabilities. We were also able to draw on other material about support staff, particularly for Projects 2 and 4. People with learning disabilities are supported by support staff, either in residential homes, at day centres or, increasingly, by personalized services such as personal assistance. All these 'hands on' supporters have a substantial involvement with money matters, as we are finding in Project 2, where we have direct evidence of some of the strategies they are using for giving help with budgeting on a day-to-day basis.

However, there are clearly areas of need here, and these are emerging from Project 4, which is about supported living. One supporter expressed the dilemmas clearly:

They do struggle on a daily basis...if a support worker goes to someone's house and they have spent all their benefits on the bookies and have got no food in the fridge, how does the support worker respond to that? Do they go into their handbag and give the person £5 so that will help them out and they'll have some food? Or do they think, well, you've got to learn from this?

The strategies that support workers use in such circumstances have to be sensitively tailored to the individual, and in Project 2 support workers are working closely with the people they support to establish budgeting strategies that work for the individual. However, we have found in that project that supporters are not receiving adequate training or supervision for many aspects of their role, and would benefit greatly from advice and support themselves.

Direct payments

None of the people with learning disabilities interviewed for this survey were direct payments recipients. However, we had access to other material (particularly Project 2) that focused on people who were receiving a direct payment in lieu of direct support, and were using that money to employ their own personal assistance. As mentioned above, this system can give people a far more independent life, and it is remarkable how often personal assistants are giving direct support with budgeting and other financial matters, often at a very detailed level.

We also asked the carers in focus groups about direct payments; one carer said that her daughter had been refused a direct payment because of lack of capacity (despite recent guidance that people can have support to manage a direct payment). Other carers said that they would not wish to go down that route, since they imagined that they would be additionally burdened with the problems of managing tax and insurance for the personal assistants.

However, we were also able to interview two family carers whose relative had a direct payment; both these families decided on the direct payment route because of inadequacies of services, and both of the people with learning disabilities had high support needs – i.e. their care 'package' would have cost a lot whether or not it was directly provided. In both cases, the individual with learning disabilities had gained greatly in terms of independence and a personally tailored service, and in both cases the main family carer had had a very important role in supporting the direct payment and managing the supports the payment bought in.

One of these carers spoke particularly about the financial security that the direct payment had given her son. The management of the payment is carried out by an independent living trust, consisting of family members and friends: the very existence of this trust gives a sense of insurance for the future. Both carers highlighted the flexibility a direct payment can bring. Personal assistants could be paid to work when they were needed by the person; money could be more easily made available for ordinary outings, entrance fees and other activities; and the burden of actually running and managing this service was not in fact as great as the burden of 'fighting social services' for appropriate support.

As direct payments and individual budgets³ are currently very important planks in Government policy for learning disability, it is important that appropriate financial support is provided to individuals and families. Some of the issues raised by the two carers interviewed related to lack of information, and lack of support and understanding from financial institutions. For instance, they had come across ignorance within social services, from care managers who did not understand how a direct payment would be costed, and from other social services employees who did not understand the implications of a direct payment. There is clearly a big need for training, especially around the financial costing of care packages, and the translation of that into direct payments.

Both carers also reported problems with banks. In order to run a direct payment, a separate bank account has to be opened, and the individual has to be able to pay their staff from that account. However, some banks had been very uncooperative about that, and had been reluctant to run a system for paying staff directly. What is often needed is a system to enable staff to be paid by 'bill payment', rather than cheque. The Co-op bank has now stepped in to offer precisely that service, and also to provide debit cards for the account. Other banks, however, do not necessarily even have good information on what they themselves can offer in this respect.

One of the carers described the encounters with banks as a 'nightmare', and in particular had experienced problems in opening an account in the name of a person with learning disabilities who could not sign for herself. These problems, of course, relate to banking in general and will be pursued further in Chapter 5. It suffices to emphasize here the urgent need for training about direct payments issues, for financial providers as well as social services staff, family members and people with learning disabilities themselves.

³ Individual budgets are a new way of organizing social care, on an individual rather than a service-driven basis. They are intended to bring transparency and user control to the process of social care management.



Chapter 5

Financial providers and support services

SUMMARY

The financial support services interviewed for this study saw their role as being aware of what the local community needed, and addressing those needs. Each service targeted particular groups of people, though none of the seven in this study specifically targeted people with learning disabilities. Either this group were not included in the service's remit or the services provided were inaccessible to people with learning disabilities.

The needs that these services were meeting were in many ways directly relevant to people with learning disabilities, such as the skills of budgeting, and how to acquire them. Yet there is a gap between what people with learning disabilities could benefit from, and the services available.

Our survey of financial support services for this review is by no means comprehensive, but nevertheless it revealed some very pervasive themes. We carried out seven 'sample' interviews with managers in financial support services, in order to find out more about the good practice that they represented, but also to gain insights into wider issues and other support provision for which they were not directly responsible. We were also able to access several interesting initiatives and projects via the Internet. This chapter will outline some of the issues that were raised in these interviews. The providers we interviewed were:

- Citizens' Advice Bureau (London borough);
- Money Max project (at CAB) (London borough);
- Debt Advice Centre (south-west England);
- Credit Union Bank (south-west England);
- Council Advice Shop (Scotland);
- Carers' project: Friendly Trust (Wales);
- Money Advice Trust (London).

Mission

The financial service providers who took part in this study were all providing a very conscious social service to the public. In particular, they were committed to supporting those who could be described as ‘financially excluded’. One manager put it like this:

Our goals are both financial and social inclusion.

There was a strong sense, through all the interviews, of being aware of what the local community needed, and of being responsive to those needs. The credit unions, for instance, were set up in response to the needs of local employees, and started off in the workplace. Another perceived need was for people to have access to both legal aid and benefits advice. An advice shop we visited was very keen to provide a ‘one-stop shop’ in this respect, so that clients did not always have to be referred on.

However, other providers felt that their services had to be very specialized, since that was the way they were funded. A debt advice service, for instance, can only deal with the specific issue of debt at the point at which clients are actually experiencing debt. They cannot stray too far into preventative work.

Other providers had wider remits. For instance, Citizens’ Advice Bureaus (CABs) said they now had a sense of a wider educational mission, in ensuring financial capability from the level of school education onwards. As one CAB manager said, the mission is wider than support to individual clients. It is also about challenging policy and practice more generally:

CABs are expected to take local action – to challenge local authorities. But wider than that, it’s about getting influence in wider legislation, to solve problems at source.

Clients of financial support services

All seven support services we spoke to were at full capacity, and were often dependent on grant income to survive. They were therefore very aware that they had to target particular groups of people, in order to raise income for their own service. An advice shop we visited was very careful to monitor its own users, and could report that its two main groups of users were:

- those who had ‘over-committed’ financially;
- people with mental health problems.

The CAB linked up with many other local support organizations, in order to target particular groups (such as church groups, minority ethnic groups, and people with mental health needs). This was all part of a policy of ‘active targeting’, as the manager explained:

The CAB records statistics of who comes to the organization. They do an annual client survey, to compare to local community statistics. This is so they can target groups that aren’t accessing the service. It’s a principle of impartiality. It goes further than saying: ‘We want everyone to come to us.’ They actively target people

who aren't using the services – for example, people with HIV, mental health service users, and young people.

This manager, like the others we spoke with, freely admitted that people with learning disabilities did not often use the service. In most instances this seemed to be because the services had not been funded specifically for that group. Additionally, the kind of advice given was not made accessible in any way to people who may not be able to read, or to understand the value of money in any sense. They therefore perceived working with people with learning disabilities as a 'specialist' service.

In other cases, of course, the nature of the service provided tended to exclude many people with learning disabilities. A debt advice centre will only deal with people who are already in debt. While they would not turn away someone with learning disabilities, it is unlikely that someone with learning disabilities would be able to come to the centre and represent themselves if they were already in debt. As the manager we spoke with put it, the basic qualification for using their service was to be able to put all the bills (even if unopened) into one carrier bag, and bring it along to the centre. This might sound like an intellectually simple feat, but it is hard for many people with learning disabilities, because of their lack of control in money matters. The manager admitted:

If I'm honest about it, if someone had a severe learning disability, they would struggle to access our service, which is designed to be there for vulnerable people, without a support worker.

In general, then, we gained a picture of many different groups of people – including people with mental health problems – who were using financial support services. This could include people with learning disabilities at the more independent end of the spectrum, and particularly those who might also have a mental health need.

It is important to emphasize the gap that exists between these support services and the population of people with learning disabilities represented in this survey. In the main, they were *not* clients of the financial support services we spoke with. Despite this gap, however, what we found out from the support services was very positive, and could be extremely relevant to many people with learning disabilities. In the final chapter of this report we will outline what would be needed to address this gap.

Providers' perceptions of problems

All the providers we interviewed were very aware of the general problems in individual financial management in the UK. They spoke of a change in culture, and the recent acceptance of a culture of debt, particularly for the younger generation. They were aware that people have always differed in the extent to which they can successfully manage a budget, and this is not always dependent on level of income. It is also a personality issue, and is very much influenced by the general expectations of society and availability of credit and loans.

One of the fundamental issues to which these managers kept returning was the basic budget sheet. One manager said:

Most people do know how much money they've got coming in, and the main things they've got to spend it on...but very few people have worked out all the things they need to spend money on, and actually written it down and added it up, and discovered whether it's too much or too little, and where they could cut back.

They were aware also that many of their clients find it hard to understand the culture of 'virtual' money, where credit and debit cards can be used instead of actual cash. There is widespread misunderstanding of banks and credit, with some clients believing that banks would actually be sources of money for them. When we recall that none of these providers was working with a large population of people with learning disabilities, it can be appreciated that lack of understanding of financial institutions will be an even greater problem amongst this group.

In terms of learning financial 'capability', one of the main perceived problems was a lack of differentiation between 'wants' and 'needs'. Two CAB managers both spoke about the importance of tackling these issues at an early age, describing how 'wants' and 'needs' can be worked at with 4-year-olds. Again, this issue has many resonances with the issues for people with learning disabilities, as described above. Through so much of their lives, people with learning disabilities are treated as children and only given pocket money. Spending is thus associated entirely with 'wants', and not with needs – until they move on into living more independently. This basic distinction is a very pertinent one for them.

Other issues that we have highlighted above for people with learning disabilities also re-occurred in the interviews with financial providers. In particular, debt was perceived as a universal problem, and the cut-throat culture of financial 'selling', including cold calls, was seen as a threat to many people on low incomes. These were the problems common to most of the clients using the services of financial providers, and were no different to those described for people with learning disabilities in this report.

Personal services

What services, then, did these institutions provide? Most of the managers described their services largely as 'personal' – i.e. provided on a personal basis, in response to individual issues presented by clients. A debt advice centre, for instance, will act as an advocate for the client, talking with creditors on their behalf. In addition to helping the client go through their outstanding bills, there is a large element of 'case work', in which the debt advisor is acting on behalf of the client.

The credit union also provided personalized services to its clients. The manager worked out, on an individual basis, a customer's bills and income. She also helped customers to work out strategies for budgeting, and supported them with their saving strategies. Part of the value of this service is its link with a very flexible banking service, in which there are no bank charges.

The manager explained it like this:

We don't let people go overdrawn. There are no bank charges. We can be flexible – if it's someone who has their benefits paid in each week, we help them budget. If it is an emergency case, we may give them a small loan, and in odd cases I might let someone go overdrawn for a day.

A banking service that is as personalized as this needs staff who really know their clients, and will inspire confidence and trust. The whole strategy to encourage good budgeting will go hand-in-hand with financially supportive banking. People with learning disabilities who would like a more 'personalized' and unified banking service would also find this approach very helpful. As we saw in Project 2, people with quite severe learning disabilities were using banks with support, and particularly liked having a personal touch, where they were known and could communicate with bank staff directly.

Promoting learning

The other main area of service provision discussed with these providers was about promoting learning. This was very well expressed by one of the CAB managers:

You've got to start with the basic life skills. Financial capability is a key life skill – it gives people control and power over their finances. Money is such an issue; that can make you feel so powerless.

The CAB viewed learning very much as a community issue. For instance, when they went into schools to run financial literacy programmes, they were aware that 'by accessing the kids, you access the parents as well'. They felt that learning was often tied up with changing cultural habits, particularly in some minority ethnic communities, where 'second hand' was considered 'dirty'. A big theme here was starting early – managers said that it was far too late to start teaching financial capability to sixth formers, just one year before they start their student debt. The CAB strategy is now to go into schools and run 'money weeks', where every aspect of the curriculum is linked with financial capability.

Members of CAB staff have clearly developed high levels of skill in supporting this kind of learning, and in assisting schools to develop awareness. For instance, they said that schools often confuse financial capability with numeracy. Instead, it is about understanding the basic relationship between earning and spending. As these managers said, people do not have to be good at maths; people with learning disabilities also need to be aware of their income and expenditure, and to talk about budgeting at the level of 'wants' and 'needs'.

At an individual level, the CAB also offered some very helpful approaches. Even if a client could not read forms, they would still consider the 'financial statement' a key document. This is a statement drawn up with each individual, matching income against expenditure.

If they couldn't read it, we'd talk them through it when they come for the interview. You'll always have people who don't understand it, and can't fill it in.

But it's the process that is important, and this is central. Money comes in, and money goes out. They'd have to engage with this in some way.

Helping a client in a 'holistic' way includes looking at a person's whole life, their opportunities and their income possibilities. Again, these aspects of advice and support would be very helpful to the people with learning disabilities who took part in the present survey.



Chapter 6

Supports used by people with learning disabilities

SUMMARY

Providers of financial support services, who do not generally offer support to people with learning disabilities, suggested that day centres, special projects or social services might be able to offer support. However, none of these are professional financial advisers. Banks were not easy for people with learning disabilities to use; the problems experienced means they are not a common form of financial support.

People with learning disabilities are as able as others to use budgeting strategies, and in this research gave several examples of ones they use themselves. These include restricting luxury purchases, planning ahead and saving regularly.

People with learning disabilities mostly turn to their families and to their own personal assistants and support workers for financial advice and assistance. It is extremely important that all these people receive support and training to fulfil their roles.

Financial support

If people with learning disabilities are not using the services reviewed in Chapter 5, where do they get their support from? When asked where people got the most support from, nearly every person with learning disabilities we talked with mentioned either a trusted support worker or a member of their family. These were not specialist financial advisers, and those who were not part of the family had often been introduced to the person with learning disabilities in relation to other support needs. For instance, the parent with learning disabilities mentioned on page 25 had support from a community nurse because of her needs in parenting.

Several of these supporters took part in the interviews and focus groups, and were clearly able to give very detailed advice about budgeting, saving and managing money to the people they supported. This aspect of support is closely examined in Project 2, where support workers are seen assisting one person with learning disabilities to construct shopping lists, and to stretch out her money in such a way that her daily need for shopping is 'managed' within her budget.

People in the interviews were asked specifically about their use of CABs, and one or two of

them remembered that they had been to a CAB for benefits advice, often accompanied by a carer. However, they did not in general perceive the CAB as a useful ongoing source of advice, support or education.

Another young person with learning disabilities was described by her parent as being very good at going to places like the CAB, to gather information. However, it was far harder for her to put it into action:

She likes to get information, that's what she spends her day doing...she's going round in circles now. She says that she didn't think charities were much help, because nobody has actually come up with anything concrete.

Parents and carers, as mentioned, tended to turn to carers' groups, and particularly valued help from workers whom they trusted – people who already knew their son or daughter, and were working closely with them. One person had had good experience of an adviser from a bank, but none had been involved in courses, or in general educational activities relating to money.

A specialized service?

Providers of financial support services often mentioned particular places where people with learning disabilities could be 'well supported' or 'understood'. They often considered this to be a specialized task, and would talk of referring people on to these services, which included day centres, specialist learning disability teams in social services or special projects. In effect, these specialized services have always been there, but do not necessarily have a sophisticated understanding of financial matters.

To consider this side of the equation, we only have to think of where people with learning disabilities actually go. Day centres are currently being changed and modernized, but traditionally they have been sources of support to many of their clients on money matters. Courses run in day centres include basic money skills, shopping and saving groups. Similarly, adults with learning disabilities also have access to a certain amount of adult and continuing education, often based in colleges of further education. These course offerings often include a strong element of money recognition and management skills. For instance, a FE course on money at the City of Bristol College included:

- recognizing coins;
- counting change;
- knowing the prices of various goods;
- using your money to go into a shop and make a purchase;
- calculating how much money your shopping will cost each day.

The problem about these courses is often that they tend to be divorced from the financial realities of people's lives. Unless people come in with 'real' shopping to do, and with their 'real' financial statement, it is very hard to ensure that the teaching is providing realistic support that will positively impact on people's lives.

Banks

In terms of support, banks were unfortunately seen by many as providing more problems than solutions. Only about half (51 per cent) of the people with learning disabilities in this review had opened a bank account in their own name. There were problems with physical access – including wheelchair access – which had been exacerbated due to the closure of smaller neighbourhood branches. In addition, nearly everyone we spoke with had had problems with opening an account in the first place, due to issues of identity (not having the right identity documents, such as utility bills) and of signature (not being able to provide a reliable signature). Some people, therefore, had been refused a bank account in their own name. Paradoxically, this included someone who was a signatory on the bank account for his own self-advocacy group, and signed cheques to pay wages for support staff.

Even when these problems had been overcome, there were often issues about not understanding how to use the bank. People generally lacked confidence about using cash machines, and felt that they needed support in managing most aspects of banking:

I don't know how to do it outside. I don't know how to do it. They've got numbers that you've got to press. You've got a pin number.

Others said they were not confident about going into a bank, and required support at all times. However, there was one example in Project 2 of someone with learning disabilities going into a local bank and having a friendly conversation with known bank staff; the personal touch is clearly key to providing a good service.

Lastly, a common problem with banks was: 'too many cards'. Credit cards and debit cards were considered equally confusing, and Visa cards in particular had led to problems in clocking up debts. As this man said,

We went down to the building society to cancel my Visa card, tore it up and chucked it in the dustbin. And got an ordinary savings account card, where I can't use Visa.

The credit union organization interviewed for this report clearly offered a lot of support to customers, in terms of managing income and expenditure, and developing plans for saving and budgeting. It would be particularly useful for credit unions to consider developing their provision for people with learning disabilities.

Self-help: budgeting strategies

Finally, it is important to consider strategies that people with learning disabilities themselves suggest. In the end, people have to help themselves, by learning to save and to budget for what they need. In the focus groups and in the interviews, various solutions were mentioned that will be briefly mentioned here.

The first and most obvious solution mentioned was simply to: 'stop buying some things for a little while', as one man with learning disabilities said. People had to learn that they had to go without, in order to save money, and this may mean going without certain luxuries they had

taken for granted. ‘Remaining vigilant’ was another general strategy mentioned, and this was often linked with others who protect you from extravagance. People had been told how to ‘be careful’, and one person said:

I just think and go: ‘Do I really need it?’

People with learning disabilities are often as capable as anyone else in learning this kind of self-denial, and sometimes may provide models to other people in the community. The general strategies of being careful obviously rely on the individual knowing how much money they have. One of the things that people often wanted support with was simply that – to have someone help them count up, or understand what money they had left, so that they would know how much they could afford.

People who knew they might run the risk of extravagance spoke of other ways they had found to stop themselves spending. Putting the money ‘in a tin’ was mentioned, as well as putting money into a bank. It was sometimes felt to be useful to have two bank accounts, so that one current account could be kept as the ‘working account’ with a back-up savings account. People who said they were naturally extravagant appreciated the routine this gave them:

It is more often that I keep spending and spending, than I am saving. I do have a money budget, which X keeps in the office for me. The money goes into Lloyds TSB, which I never touch. I am not allowed to anyway. I feel OK with that money budget – it is a good thing, yes.

Planning ahead, saving for ‘bigger’ items that people desired, was mentioned as a way of ensuring money was always there for essential items. Many people, as we have mentioned, had limited access to particular amounts of money. As long as these systems were worked out with the person concerned, these seemed to be good working solutions. Similarly, people mainly felt that payment of benefits directly into their bank accounts helped them to budget. One person said:

It saves you going in and if you have got an allowance book, you would be tempted to spend...eat on like junk food rubbish, like doner kebabs or games, just go out and buy a game and that.

However, the evidence from Project 4, about supported living, is that supported living tenants generally said they preferred the personalized system of benefits books. The old way of getting money from the post office weekly, then dividing money up to pay for different things, was far more concrete and understandable.

Despite the plethora of problems and financial issues faced by people with learning disabilities, these examples show that they are often able to sort out their own problems, with the right support. They need not be ‘financially excluded’; instead of finding money a stressful subject, the management of one’s own budget should bring satisfaction and a sense of control. The final chapter of this report will consider some ways of supporting people more effectively.



Chapter 7

Conclusions and recommendations

Having considered the problems faced by people with learning disabilities, the issues raised by their carers and families, and also the services offered by some very proactive financial support services, it seems that there are several major gaps in provision. Many of these could be addressed if the barriers were broken down between ‘specialist’ learning disability services and financial support services.

It would be useful to have funding for financial support services to address the gaps in the following three areas:

- 1 For people with learning disabilities themselves, there is a huge gulf between the ‘Mars Bar’ and ‘managing the flat’ – between small-scale spending on personal items, and managing living expenses. This is a very wide gap to span and there seems to be an absence of solutions to the stages of learning and independence that lie between these two extremes.
- 2 For carers and families, the gap perhaps lies between their wish to protect their relative with learning disabilities (and indeed the need to protect the whole family’s finances) and their wish to support increasing independence. There are potentially grave conflicts between these two impulses, as family members are often interdependent in financial terms. Therefore, although families may want to encourage greater independence, some families will find it very hard to square this with the financial needs of the whole family.
- 3 Finally, there seems to be a gap between services that provide generic support to ‘excluded’ communities (including debt services, CABs and advice shops) and the special services that generally support people with learning disabilities.

The recommendations we will make here draw on insights and solutions suggested by families, by people with learning disabilities and by financial providers. Essentially, they are geared towards ways of filling the three areas of gaps in provision.

From the Mars Bar to managing a flat

People with learning disabilities have a wide spectrum of abilities and independence skills. Like others in the community, there is also a wide spectrum of personalities in relation to spending. However, this report revealed two significant groups of people in relation to money matters, which were relatively discrete.

In the ‘Mars Bar’ group, people have:

- very little access to their own money;
- supporters, carers or family members who control their financial affairs very tightly;
- living arrangements at home with family, or in residential care homes;
- pocket money, or small amounts, for spending on personal items such as a Mars Bar or the occasional CD.

In the 'Managing your Flat' group, people have:

- independent supported living arrangements, including direct payments provision and personal assistance;
- technically, full access to their own money;
- the expectation that they will be able to budget for accommodation, food, travel, bills;
- support workers who may be able to help them budget, but who require support themselves to learn this task.

People in this study have spoken of the importance of learning financial independence in small, concrete steps. Yet, there seems to be little opportunity for people to actually take these steps in realistic ways before they are exposed to the difficulties of managing independence. No one would want to impose unnecessary stages of 'readiness' or learning before allowing people to move out independently. However, people would benefit from much more supported learning at the stage of moving into independent living. Such learning packages should be shared with support workers, and should ensure:

- that the person with learning disabilities is informed in easy-to-understand ways about his or her financial position;
- that the person with learning disabilities is in control of financial matters – i.e. enabled to make real decisions about how to spend money;
- that safeguards are put in place so that independence can be achieved with minimum risk.

Carers and supporters: From protection to supporting risk

Carers who took part in this study were well aware of the risks faced by their family member with a learning disability, and were additionally aware of the difficulties of maintaining adequate family finances. When people with learning disabilities moved out of the family home, they generally had support workers – and family members, who are often still involved and concerned for their welfare. All these supporters and carers face the tension between the desire to protect the person with learning disabilities, and the desire to help them learn independence.

Carers in this study found that sharing information about financial matters was useful in itself. At the focus groups, carers frequently broke off from directly answering questions in order to share information about benefits, sources of finance or ways of handling bank accounts. They were anxious to support each other, and said in fact that this was the main way in which they normally found out new information. Good independent carers' groups can also help, as this carer said:

I think the important thing is to be able to access when we need advice and support. Good, sound, independent and reliable information, and practical help about what not to do.

In trying to get this help, carers often felt frustrated because they were not considered to be financially 'responsible' for their son or daughter. They urgently wanted advice in their own right, not just as adjuncts to their relative with learning disabilities. Some of the carers had found written information very useful (for example, a guide with addresses and contact details of other organizations), and mentioned particularly the need for information on wills and trusts.

The issue of family or home carers was discussed particularly with the CAB, where the managers mentioned a 'second tier' project, directly designed for those who might be advising people who have money problems. This project provided actual courses for people who work in housing associations, for social workers, community workers and so on. The aim was for them firstly to understand how to analyse their own finances, and then to go on to think about how they could advise their clients. Additionally, the CAB was training up 'money mentors' who were perceived as peers to the people they were advising. The idea of both these schemes is to target people who will be known and trusted by the people whom they advise.

Although both these ideas are very valuable, this report has arguably taken us a step further. In debt advice and other forms of support, managers did say that they would talk with a carer if he or she came along, together with a person with learning disabilities. It would seem that this is going to be absolutely essential, if people are to be enabled to take even the first step of learning about their own finances. Our recommendations would therefore be:

- 1 Ensure there is more provision for direct advice to carers and family members about financial matters, especially as the young person with learning disabilities approaches adulthood, and also in relation to wills.
- 2 Train carers and support workers in giving financial advice and support to people with learning disabilities.
- 3 Ensure that carers and support workers can have rights to advice alongside the person they are supporting, and are not excluded unnecessarily.

From specialist services to generic financial support services

The financial support services interviewed in this study were not, in the main, supporting people with learning disabilities. However, most of the financial support work being carried out was nevertheless very appropriate. On examining the actual activities of the financial support services, they do appear to be potentially very relevant to people with learning disabilities. The two aspects that generally appear to be missing are accessible information, and a holistic approach that would include supporters and carers. We have already mentioned the latter issue. Below we will focus on accessibility.

The providers we spoke with were all well aware that they needed to support clients who

had literacy problems. In most cases, this involved reading through information with clients, and helping them with form-filling, on an individual basis. Additionally, the CAB spoke of educational work on financial capability, including the work described above in schools. However, very few of them had gone beyond that to change the access to information they offered:

The CAB hasn't done anything specifically about 'easy information' – for example, putting pictures with words, simplifying language, putting information on tape or CD.

The advice shop we visited did have a simplified leaflet, with symbol/pictures, but this was the only example we saw of something accessible in use. Examples of financial guides on the web, equally, are often not fully accessible to people who have real problems in reading. For instance, the very useful guides from the Financial Services Association (FSA) have far too much text and no attention to 'easy English' at the level that most people with learning disabilities would need.

However, some good examples of accessible information about financial matters have been reviewed for this project. For instance, MENCAP has an accessible web page to assist people in understanding financial matters, and local areas have produced information that is very useful; the Barton Hill Advice Centre in Bristol produced a web-based guide, together with Bristol and South Gloucestershire People First. Both of these are referenced at the end of this report. In order to address this aspect of accessibility, providers need to take on board certain basic principles:

- work with people with learning disabilities to develop information;
- learn skills for making written text easier to understand;
- provide pictures and/or symbols;
- provide audio versions of text;
- give people the information they need in bite-sized chunks.

It may well be that specialists in learning disability could work with financial support services, in order to help them develop skills with people with learning disabilities. The best trainers of all are people with learning disabilities themselves, and many self-advocacy organizations have now started to get involved in training, particularly around accessible information. The barriers between 'specialist' and 'generic' financial supports need to be broken down, and the best way of doing this is to directly involve people with learning disabilities.

Further research

Although this report is based on a relatively small sample of people with learning disabilities and carers, we have been able to draw on wider research, involving people with learning disabilities who are parents, young people reaching transition, people using direct payments, and those in supported living. We have also pointed out the problems relating to support in money matters for people with learning disabilities. However, these points are based on slim (and sometimes conflicting) evidence. With the emergence of a new workforce of

‘personalized support workers’, there is a need to carry out further analysis of workforce skills in this area. In particular, it would be useful to have further evidence of financial support strategies used in the family home, and to compare these with strategies used by support workers and paid care staff.

The issues faced by financial institutions in relation to people with learning disabilities are very important, and this report has only touched on some of the evidence, highlighting difficulties with access, confusion and lack of support from banks and other financial institutions. With further modernization of services for people with learning disabilities, there will be more moves towards community living, individualized support and use of ordinary, mainstream facilities. Livingstone (2007) gives further information about how banking services can be adapted for people with learning disabilities, and gives some practical advice and guidance for people with learning disabilities as well as for banks themselves.

In the light of this, it would therefore be very useful to conduct a larger-scale, in depth analysis of particular groups of people with learning disabilities, as they venture into more independent living. These could include:

- a sample of people using direct payments;
- young people moving out from the family home;
- people who are tenants in their own right, or who do not use service supports.

The three areas of ‘gaps’ or barriers outlined above could all be addressed through action research projects, which would enable us to learn more about what is needed and what works well. In particular, this report has sampled some of the financial support providers, including the CAB and other advice services, whose aim is to provide support to those who are ‘financially excluded’. Further research should enable us to develop a greater, qualitative understanding of how these services support financially excluded clients, and how their services could be extended to include people with more severe learning disabilities.

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