

Money, rights and risks: Financial issues for people with learning disabilities in the UK

This is a review of financial issues for people with learning disabilities and their families, across the UK. This group of people is moving toward more independent management of their finances, for a number of reasons. These include policy moves towards independent living, choice and control, as well as mechanisms such as social services direct payments.

Key findings

- The study found that many people with learning disabilities had little control of their own resources. They were mostly given ‘pocket money’, which they spent on small non-essential items. Prior to living independently, very few were encouraged to consider managing a budget for items such as food, accommodation and heating.
- People had few opportunities to improve their financial knowledge. Personal incomes were low, and some had taken on credit that they did not understand, and could not afford. Overall, many found the issue of money a very stressful subject.
- The low income received by people with learning disabilities led in some cases to a potential ‘benefit trap’. For instance, taking paid work could jeopardize the benefits the family depended on. Family carers of adults felt responsible for their son’s or daughter’s finances, and mostly took control of them.
- Financial support services tended not to offer services that were accessible to people with learning disabilities, nor did they target them. However, the services they were offering could be directly relevant to the needs of people with learning disabilities.

Key recommendations

- People with learning disabilities need planned financial support packages when they move into independent living. They also need safeguards, to ensure minimal financial risk.
- Family carers and support staff need advice, information and training in offering financial support.
- Financial support services could be funded to work specifically with people with learning disabilities.

What’s inside

Introduction
Policy context
About the study
Issues for people with learning disability
Issues for carers and families
Financial providers and support services

Introduction

This is a summary 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.

Policy context

Recent policy moves are supporting people with learning disabilities towards greater independence, both financially and in terms of their support requirements. The introduction of social services direct payments 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. Supported living opportunities are increasing, which means that an increasing number of people with learning disabilities will be living independently, with supporters visiting on a regular basis. At the same time, the move to the payment of benefits by automatic credit transfer means that people with learning disabilities need access to banking services and an awareness of financial issues. This represents a huge change for people with learning disabilities.

About the study

The review drew on a wide range of recent and ongoing research, and ran three focus groups for people with learning disabilities (N=25) in different areas of the UK 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. Discussions were also held with two family members of people with learning disabilities who received direct payments. Interviews with seven managers in financial support services found out more about examples of good practice and helped to gain insights into wider issues.

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 this review, there were many people who did not understand money. At one end of the spectrum, 40 per cent were not sure about coins, notes and their value. However, as many as 86 per cent were confused over benefits, income and expenditure. Money was a difficult topic; problems and worries relating to money could result in mental distress, and this had happened for at least two out of the ten interviewees who were in supported living.

Seventy-four 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. Many people with learning disabilities were only given what amounted to pocket money, which they spent on small personal items, holidays, snacks or sweets. They had little opportunity to learn about budgeting for bills, food shopping or major expenditures.

People with learning disabilities' views on financial issues

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?'

People with learning disabilities said that banks and other financial institutions were difficult for them to use. Only 51 per cent had a bank account in their own name. This was often because of inaccessible information and procedures. In addition, 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.

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.

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 with parents or on college courses.

Issues for carers and families

Families found it hard to separate out 'financial' issues from all the other issues of supporting a person with learning disabilities in the family home. They were often engaged in what they perceived as battles to obtain appropriate supports for their learning disabled member.

Family 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. However, they continued at this age to be the main source of support and advice to their son or daughter on financial matters, and on helping them to learn new skills to handle money.

In some instances there were examples of good, 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. However, both paid support workers and family carers need training in financial matters, in order to teach and support people with learning disabilities. They suffered from a lack of clear information about matters such as capacity, financial rights, benefits and wills.

Families of direct payments users with learning disabilities felt positively about the opportunities offered. However, they needed better advice, support and understanding from banks and from social services.

Financial providers and support services

Customers of services such as Citizens' Advice Bureaus, debt advice or credit unions were offered personal, individual advice. However, 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.

These services highlighted many societal problems, including a growing 'debt culture', the difficulty of understanding debit, credit and interest rates, and the need to learn financial capability. These are all aspects that affect people with learning disabilities.

Some people with learning disabilities had attended courses about money skills in FE colleges or day centres, and received financial support either from parents and carers, or from paid support staff. However, banks were seen by people with learning disabilities as confusing and unresponsive. People described many self-help strategies they had developed, for saving money and for budgeting.

Recommendations

- Services such as advice shops and the Citizen's Advice Bureau 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.
- Family carers and support staff 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.

Further information

This summary and the full report, *Money, Rights and Risks: A scoping review of financial issues for people with learning disabilities in the UK* by Val Williams, David Abbott, Jackie Rodgers, Linda Ward and Debby Watson, are available in print, pdf and Word from Friends Provident Foundation (foundation.enquiries@friendsprovident.co.uk and www.friendsprovidentfoundation.org).

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