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Making ends meet – what it's like for people with learning difficulties living in the community on low incomes

The Money, Friends and Making Ends Meet Research Group is part of Building Bridges Training, a community interest company based in the West Midlands, who want to make a difference through training and research.

We are a small group of people with learning difficulties who don't get support from services and this inclusive research project is about our lives and experiences. At our meetings we talked about who we have as friends and supporters and how we manage our money and try to make ends meet. We thought about our identity, what we think having learning difficulties means and that we sometimes need support.

The research project lets our group have a voice and helps other people to understand what life is like for us. We are happy to be described as disabled or having learning difficulties.

How we did our research

The research was done from the approach of looking at the barriers in society that make life difficult for us and people like us. This is known as the social model of disability. We got our information in lots of different ways, including meeting as a group ten times. We also used an action research approach where we went about trying to sort out problems and issues together so we could find out what some of the barriers were, such as problems at Jobcentre Plus. Then, with support, we looked at what we had said to find the themes which are the main issues in our lives.

Our research project took place between July 2010 and June 2011. Eleven people were involved altogether. We all live in the West Midlands and went to special schools when we were young.

Money and making ends meet

We all get different benefits; some get Jobseeker's Allowance, some get Income Support and some also get lower rate Disability Living Allowance. Most of us have no cash for at least a couple of days before our benefit comes. For those of us with only Jobseeker's Allowance it could often be up to six days. This means we might have to go without electric or food and have to borrow money or food from our friends and family for us and our pets.

So making ends meet is always hard for us. We manage by having a little loan from friends and family, usually £10, but we find this really hard to pay back as we need all our money when we get it and sometimes our family let us off, or we owe it to them for several weeks. Most of us have at least one major debt with a phone, catalogue or utility company.

Disability Living Allowance

Some of us get Disability Living Allowance and some of us don't. Those that get it only get the lower rate for care but it makes a BIG difference to get this money every four weeks. One of the group did get Disability Living Allowance in the past and, through the research project, we found out it had stopped in 2006 because she didn't return a form which she couldn't read. The Welfare Rights Team helped us to reapply and we got it back but not for the missing five years, even though the reason was because of her disability!

We think it's unfair that not all people with learning difficulties get Disability Living Allowance.

Big debts

We've all had at least one big debt, with all sorts of people. One person had a debt with a catalogue and a mobile phone company because they sold her a monthly contract she didn't need and couldn't afford. Then she had lots of letters from debt collection agencies that she couldn't read or understand, and then frightening phone calls from the company. Lots of people get into debt with water rates.

It's really hard to repay debts as there is only enough money in our benefits to live on. One person is also paying a fine. People who have set up direct debits to pay bills can get into more debt when there is no money in their accounts to pay the bill so the bank charges an £8 fee – which can happen twice in one month. One couple had a cash loan years ago from a credit company on behalf of someone they knew who needed the money, but he never paid it back and this led to a lot of problems and falling out.

Most people are aware that furniture credit shops on the high street and door to door credit companies work out too expensive and they can't afford the repayments.

What we think our research tells us

We have been thinking about our lives and other people like us – that is, people with learning difficulties who don't get help and support from formal services. We have very few friends who know things and can help us. Most people in our social networks are friends and family members who also have some level of learning disability. Lots of us have had bad experiences with past relationships. We are not in contact with many people who can support us to stop us getting into difficulties in the first place. We are not supported by funded voluntary organisations but some of us get help from local churches and volunteer-run projects, particularly one small local charity which gives out second-hand furniture and home furnishings.

Churches are important to six of us where we feel welcome and respected and can get help in the week if we need it. It makes us feel important to be part of things like singing in the choir and helping with making tea and coffee.

Money management and managing appointments are very difficult for us as people communicate to us with letters we cannot understand. Other places, like Jobcentre Plus, expect us to be able to write and fill in forms. We find it hard to make ourselves understood on the phone and it's easier to go in person to see people when you can. If people know we have learning difficulties they are more helpful and kind to us.

A lot of the problems we have in day to day living because of our learning difficulties aren't recognised by the people who decide if we should get support, Disability Living Allowance or concessionary bus passes.

We think some things aren't fair for us and people like us. For example, some people get a lot more benefit than us. Not everyone can get a concessionary travel pass and it's easy to get into debt. Some of us would like to work but we don't think there are many jobs for people like us.

We feel we do not have a voice or opportunities to contribute to our communities. There are many difficulties in our lives, like having no work, no money, few friends and not much confidence. This means that most of us feel for most of the time that we live very limited and unfulfilled lives. People with more confidence and know more people outside their group of family and friends have more things they are involved with.

What would help people like us

We think it's really important for people like us to have a place in the local community we can just pop into when we have a problem, where someone can read and explain letters and make complicated phone calls on our behalf. Some people need regular help with coping day to day especially managing their post and money.

People like us need support when we have to go for appointments as it might be too far, we might have no money to get there or we are put off going as we may be too frightened. This is especially if they have to go to the hospital or to a new employment scheme.

People with learning difficulties need a lot of support if they have children, especially when they are teenagers – but also when the children are taken away. They need a clearer explanation about why they were taken and help to cope with the loss.

Letters should be written in easy English, with just a few words and some pictures so we know what they are about.

We really value the friends we made in the past and they support us a lot, so it's good to have places to go or groups to belong to where we can see them and it costs nothing, so we can keep our networks.

Small charities that give furniture and foodbanks are really good but not every area has them so it would be good if there were more.

It would be really good if direct debits could come out of our benefits every four weeks to help us manage our money. For some people it would help to have some payments taken out of their benefits before they have them to stop them getting into debt.

What next for the research group?

We are going to continue to meet as a group every month. We will keep writing articles and hopefully do some talks. Two of the group are also now trainers with Building Bridges Training.

We would all like to say a big thank you to the Big Lottery Fund for the grant which paid for the meeting costs associated with this research project and the printing costs of our report.

For further information or a free copy of the full report please contact:
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