



Nick Hopkins Consulting

Financial Inclusion Experiences of People with Ataxia

Nick Hopkins Consulting for
Ataxia UK

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Contact Details:

Nick Hopkins,
Director,
Nick Hopkins Consulting,
41 Carolside Avenue,
Clarkston,
Glasgow,
G76 7AD
Tel: 07891 600078
E mail: nick@nhhrconsulting.co.uk
Website: www.nhhrconsulting.co.uk

Section 1: Introduction

In October 2019 Ataxia UK commissioned Nick Hopkins Consulting to carry out a research project exploring the financial inclusion related experiences of people with ataxia.

The aim of the research was to provide an evidence base to guide Ataxia UK's future financial inclusion related information, support and advice provision and campaigning/ influencing activities.

The most immediate decision to be taken by Ataxia UK related to the possibility of partnering with Scottish Huntington's Association, using its existing financial inclusion service to reach out to people with ataxia. With this in mind the interviewee sample was designed to ensure a strong perspective from the devolved administrations in the findings.

The report is divided into the following sections:

- Section 2 sets out the work undertaken by the consultant in delivery of the project.
- Sections 3-5 set the context for the financial issues covered in the rest of the report, focusing on experience and timing of diagnosis, the impact of ataxia on respondents' daily lives, and on their employment and housing situations.
- Sections 6 and 7 focus on the perspectives of people with ataxia on their financial situation and the extra costs they face associated with ataxia.
- Sections 8-10 focus on three sets of financial inclusion issues relating to; engagement with the benefits system; debt and money management; and financial planning/ use of financial products.
- Sections 11 and 12 focus on experiences of engagement with other advice services, and with the information, advice and support provided by Ataxia UK.
- Section 13 focuses on views of potential future engagement in financial inclusion work by Ataxia UK.
- Section 14 sets out conclusions drawn from the report which are relevant to future activity by Ataxia UK in this field, and makes recommendations based on those conclusions.

The consultant would like to thank all those from Ataxia UK who gave their time to assist in the production of this report, and most of all those people with ataxia and carers who gave their time to respond to the survey, be interviewed or participate in the focus groups, and who spoke so honestly and openly about their experiences and perspectives, even when covering potentially difficult and private issues.

Section 2: Methodology.

This report is based on:

- A survey of people with ataxia who are engaged with Ataxia UK in some way from which 254 responses were received.
- 4 interviews with staff and board members of Ataxia UK
- 26 interviews, and 3 focus groups, with people with ataxia who have engaged with Ataxia UK in some way.

Survey

The survey was disseminated in both hard copy and electronic formats:

- The hard copy format was distributed through the Ataxia UK Autumn/ Winter magazine.
- The online format was disseminated through direct e mail, the provision of a link in the article accompanying the survey in the magazine, and through promotion through Ataxia UK's online forums and social media channels.

Hard copies were returned to Ataxia UK through a Freepost address, with the data being entered by the consultant.

The hard copy had been produced earlier than initially intended due to the tightness of print schedules. Due to this, a very small number of minor changes were made to the online survey which was disseminated shortly afterwards, relating to information being sought about the type of ataxia impacting on respondents and a small number of sense edits.

Characteristics of respondents

Age, Sex and Ethnic Origin

- Slightly more men replied to the survey than women, 54% to 46%.
- A majority of respondents, 63%, were 55 or over with one quarter of respondents aged between 55 and 64.
- Only 20% were aged under 44.
- 89% of respondents defined themselves as white British/ English/Irish/ Scottish/ Welsh, 5% as white 'other'. Fewer than 2% defined themselves as being from Bangladesh/ India/ Pakistan or being Black African.

Household Status.

- 54% were living as part of a couple with a partner, 46% were not.
- 16% had dependent children living with them, 84% did not.
- Of those with children living with them; 44% had one child, 29% had two, 10% had three and 17% had four or more.
- 86% had no adults in their household other than their partner or grown up children, 11% were living with their parents or members of the older generation, 5% with siblings or other adults.
- Only 6% of respondents' households contained more than one person living with ataxia.
- 34% were living alone.

Location.

- Respondents were spread across the UK; 17% came from SE England, 13% from SW England.
- 8% of respondents came from Scotland, 5% from Wales, and less than 1% from Northern Ireland.

Housing Status.

- Respondents were slightly less likely to be living in a home that they owned than the UK general population, although, perhaps reflecting the age of respondents, the figures for paying off with a mortgage and owning outright were almost reversed:
 - 43% of respondents were living in a house they owned having paid off their mortgage, against 21% in the general UK population.
 - 18% owned their own house which they were paying off with a mortgage, against 43% in the UK general population.
- Respondents were significantly more likely to live in social rented housing than the UK general population and significantly less likely to live in the private rented sector, perhaps reflecting both the importance of the social rented sector for disabled people and the age of respondents.
 - 23% were renting from a social landlord, against 15% in the general UK population.
 - 10% were renting from a private landlord against 21% in the general UK population.
- 6% described their housing situation as 'other'.

Staff Interviews

The consultant carried out four interviews with staff/ board members from ataxia UK. This focus on both their understanding of the financial issues facing people with ataxias, and their perspective on the impact and potential additionality of having access to a financial inclusion service.

One of the people interviewed was herself affected by ataxia. That interview was particularly critical in influencing the design of the aide memoire, and her feedback has been included in this report alongside that of other interviewees with ataxia in the sections that follow.

Interviews and Focus Groups with People with Ataxia

Recruitment to interviews was carried out through:

- Requests for interviewees carried in the magazine and made on hard and online versions of the survey.
- Direct e mailing of people engaging with Ataxia UK.
- Advertising through Ataxia UK's online forums and social media channels.
- Direct approaches to people with ataxia in contact with Ataxia UK.

Recruitment to focus groups was carried out through:

- Engagement with existing support groups in Glasgow and South Wales.
- Publicising of the opportunity to talk about financial issues to people with ataxia in London and SE England.

Interviews and focus groups were semi-structured, based on an aide memoire shared with Ataxia UK for comment, ensuring both that key issues were covered and that interviewees could explore issues of interest to them in detail.

26 interviews were carried out with people with ataxia, four of which were carried out in written format reflecting the preferences of those involved, 22 of which were carried out on the phone. Reflecting part of the initial stimulus for the research, 7 of the interviews were with people from Scotland. 13 were from England, 3 were from Northern Ireland and 2 were from Wales.

Focus groups were held in three cities; Cardiff, Glasgow and London. In total the focus groups involved 22 people, 18 of whom had ataxia and 6 of whom had caring responsibilities for people with ataxia.

A total of 48 people were therefore involved in the qualitative element of the project. 27 were male, and 21 were female.

The age range of people involved in interviews and groups was:

- 18-24: 1 person.
- 25-34: 6 people.
- 35-44: 4 people.
- 45-54: 14 people.
- 55-64: 15 people.
- 65-74: 7 people
- 75 plus: 1 person

In the report that follows, each respondent is assigned a name which is not held by them or any other interviewee, but which indicates gender and maintains the humanity of the respondent, and to indicate respondents' age within broad bands.

Section 3: Diagnosis with Ataxia

Survey Responses

Type of Ataxia/ Age of Onset

- Three quarters of respondents reported having cerebellar ataxia, 16% indicated that their ataxia was defined as 'other', with only 9% of respondents reporting that they had Friedrich's ataxia.
- 51% had first experienced symptoms after the age of 45, 26% of all respondents between the age of 45 and 54.
- 15% had first experienced symptoms under the age of 18.

Interviews and Focus Groups

Experience and Timing of Diagnosis.

For many participants the experience of being diagnosed was extended. Some clients in middle age or older had experienced the onset of symptoms in early adulthood, but had only been diagnosed much later, in one case about 20 years after first having balance issues. Often those symptoms had been noticeable but relatively minor and they had been seen by the person affected as just being the way things were, a something that was not quite right but not of major concern.

One participant gave a sense of the clues that had indicated something was wrong, and the way he had adjusted to cope with them, another of a slightly different set of symptoms with which they had simply lived:

'I felt I was coping OK with symptoms but when I was 26 they got a little worse. I felt they needed investigation. There are little things that I didn't think of all the time. Things that I had always lived with, like not being able to walk down the stairs without holding onto the bannister. I couldn't bounce a ball properly whilst walking until I was 10, I wasn't very sporty, that's quite common with ataxia.' (Liam, 35-44)

'They first appeared in my 30s, I didn't have any idea what it was at the time. I used to get tiredness and lightheadedness, I thought it was the time of the month causing it. It was probably more severe in my late 40s. I'd always had a really bad feeling, I thought that something was wrong with my ear. When I was younger I was riding a bike with my daughter and I keeled over. Things like that.' (Anne, 75 plus)

Many described how their first symptoms had given them a sense that something was wrong. One participant remembered sitting down with her husband to talk about how she was feeling because she was aware that something wasn't right, because she was feeling a bit 'wobbly', others spoke about friends or relatives noticing that something was wrong. In contrast, some had assumed that they were experiencing normal human clumsiness:

'I was 19/20. I fell over and was having a wobble. I thought I was being clumsy, but I wasn't.' (Sian, 25-34)

Diagnosis had often come after seeking help when symptoms of their condition had worsened or they had not been able to cope with them as well as they had managed previously. On other occasions health issues had triggered engagement with health professionals who had identified straight away that investigation was required. 'Anne'

had sought help with a heart issue, and her unusual gait had been noted by the doctor who saw her enter his consulting room, and who had initially thought she might have a brain tumour.

For other participants their own diagnosis had come after other members of the family had been diagnosed, sometimes their children. This could be after a long period of living with symptoms, or could prompt earlier diagnosis or even diagnosis whilst asymptomatic:

'I was first diagnosed when I was 44. I've really had symptoms all my life. I have had ataxic movements for a long time, and deformity of my feet. It's caused me problems all my life. I was diagnosed in September 2009, it was a long process to get diagnosed, when my daughter was diagnosed I asked if I could take a genetic test at that point.' (Frances, 45-54)

'After struggling most of my life to describe what I had, and feeling people didn't believe me, it was a great relief to get a diagnosis. Two out of three of my daughters started having similar symptoms and it wasn't until we took them to the neurologist about 7 years ago that they were diagnosed with a genetic blood test, and we then knew what I had, I was formally diagnosed by having nerve conduction tests. Before then the condition was described as 'something like epilepsy' and I had various one off and continuous EEG tests, all to no avail.' (Greg, 55-64)

However some family responses could delay their access to diagnosis:

'My father and grandfather had the condition, my mother kept it from me. She would tell me that his problems were because he had been in the war. I just accepted that.' (Mary, 55-64)

Carers of young people/ children with the condition, and some of those affected as children reported that symptoms had been very clear from early on, with mobility particularly affected, but that even in these circumstances diagnosis could take some time:

'We noticed my son was different as soon as he could walk. The symptoms were more obvious by the time he got to five. The GP and the consultant didn't know what it was at first.' (Hamed, 45-54)

For others, childhood issues had been interpreted as relating to other health problems, one participant described herself as struggling through school and being diagnosed variously with dyslexia and then dyspraxia.

A number of participants spoke about their symptoms initially being investigated as being caused by other conditions, including brain tumours, epilepsy, Huntington's, multiple sclerosis and Parkinson's, and less seriously as being the result of ear infections. Some of those investigations had been quite extensive/. Some reported that the neurologists they had initially engaged with had not been ataxia specialists.

'I had symptoms when I was 27. I began to have issues with my balance, I was losing control of my feet. I only got diagnosed 5 years ago. It took a very long time. They couldn't work out what it was. They thought that I had MS. I had a scan and a lumbar puncture but nothing showed up. They still can't find out what is causing the cerebellar ataxia.' (Graeme, 55-64)

A small number of participants had experienced very sudden onset of symptoms, followed by relatively rapid diagnosis. One had had a lumbar puncture shortly before going on holiday, and then had had a breakdown whilst on holiday, and at one point had had to be sectioned under the mental health act.

Another spoke of his experience:

'It was sudden onset. I was sitting on a bench. I struggled when I got up. I thought that I had been sitting too long, and that it would go away, but it didn't and I kept losing my balance.' (Malik, 65-74)

For others the situation was not so much about the sudden onset of symptoms, as there being a particular occasion when they remembered thinking that something was not right:

'I used to do boxing and went back with my step son. I found that I couldn't do the things I used to do before. I was diagnosed in 2007, that was about 10 years when I knew there was something wrong but couldn't put my finger on it.' (Peter, 55-64)

Feelings about Diagnosis

Broadly positive responses

A number of participants simply reported that they had felt that their condition at least had a label or a number, for some that was their predominant focus:

'I didn't feel much different after diagnosis. It hasn't changed my attitude to life or anything. Nothing has really changed, apart from now I have a label as to why my balance is off and things like that.' (Danielle, 25-34)

A number of participants felt a degree of relief that they had a diagnosis, particularly where they had been dealing with the symptoms of the condition for most of their life, to the point in one case of describing themselves as being 'glad'. This relief could even involve feeling relief that they knew something of how their condition would progress. For one participant the diagnosis at least raised the possibility that research might one day mean she could be cured.

One participant felt that the diagnosis at least allowed her to think of how she could fight back against the condition. She had feared being told that she could no longer go to the gym to exercise, but had been heartened to be told that would actually be good for her. Another identified her decision to take a positive attitude towards the condition as being critical, alongside the support she had from friends and family:

'I had never heard of it before, I decided to take it in my stride. I coped pretty well, I think it's important to be positive. I also get support from my friends and partner....I think it's great that you get more disabled people on TV.' (Melanie, 45-54)

There was also a sense from a number of interviewees diagnosed in middle or older age who were taking the attitude that although the condition would limit what they could do, it would not necessarily be life shortening for them, or, in the case of one asymptomatic individual, that they might never get the condition:

'I read up that it was progressive, but not usually fatal' (George, 65-74)

'They told me that I might start getting symptoms at 92, but I might die at 83.'
(Rebecca, 45-54)

'I expect to die with ataxia, but not die of ataxia.' (Ray, 65-74)

Others felt that there were other conditions that could have been worse to have:

'I thought that I had MS and that was the explanation for me being a bit skewhiffy. I was glad that I hadn't got MS. I know that everyone deteriorates, but you deteriorate quicker with MS.' (Wayne, 55-64)

For some of the participants, ataxia felt as if it was something that they had always lived with, and they had reacted to it in quite a matter of fact way:

'I was only 13 when I found out. I just ignored it, I didn't think it was a big thing, in those days they didn't know much about it. When you are young you think differently, I just got on with it.' (Gary, 55-64).

For some, their feelings at diagnosis had not left a lasting impression, in some cases because they had families in which the condition was present and they had always expected to be affected by it.

Issues around awareness

Many participants reported not previously having been aware of their condition, and being uncertain about what it was when they were diagnosed. There was a sense from some of the broader lack of information about and understanding of the condition:

'I had several MRIs, I've been to five neurologists, but no one can work out exactly what it is.' (Malik, 65-74)

'I didn't know much about the condition [at time of diagnosis]. I still don't. I don't think anybody else does. I wanted to know what the future held, but the neurologist said that they couldn't say, everyone is so different.' (Ray, 65-74)

Negative responses

For a significant minority of participants, diagnosis had triggered very negative feelings.

Participants had sometimes experienced diagnosis as a real shock:

'When I got the diagnosis, I thought 'Shit, shit, shit'. Externally I was quite calm, internally I had all sorts of questions about what it would mean for me.'
(Jimi, 45-54)

Feelings of isolation sometimes accompanied feelings of depression, partially driven by the sheer rarity of the condition/ some forms of the condition. People could also feel quite unsupported, including one of the participants who had received a diagnosis after her son and was asymptomatic:

'This type of ataxia is very rare. I felt really isolated at this point. Even in the online forums, no one knew what it was.' (Frances, 45-54).

'When it was confirmed it was like you have got it, now go away. I have had nothing.....I got my diagnosis on the back of his, and nobody has spoken about it at all to me. It's 'see you later' and will go and look for something else with your son. It's been more bewilderment than a negative impact.'
(Rebecca, 45-54)

Thoughts about families could be quite complex. 'Frances' reflected on the impact of the condition being genetic:

'I do feel guilty that I gave my daughter this thing. I know it doesn't make sense and people have told me it's not my fault, but when it's yourself, it feels like your own fault and you don't want to think that.' (Frances, 45-54).

Some were worried about being a burden on others in the family, whilst others turned straight to their family for support:

'At first I was quite scared. I didn't know anything about it. I had heard the word but I didn't know anything about how it might affect you. When I got it my husband was at work and I couldn't get hold of my parents. I went home and cried and then my husband and I stayed up all night looking for information on line. There was not a lot of information about type SCA8, there was a lot more about Friedrich's Ataxia.' (Rachel, 45-54)

For 'Rachel' the internet had been a source of help, giving her at least some of the information she needed to think through what was happening to her, for others consulting the internet was a potential trigger for depressive thoughts:

'Only the things you read on the internet, you should never do that. They tell you things like it reduces your lifespan and you might end up in a wheelchair.'
(Danielle, 25-34)

Social awkwardness

One participant explored in some detail the dilemmas she had experienced thinking about who she should tell about her condition:

'I faced the choice of telling everybody or telling nobody. I did tell everyone that I knew well, I told the school mums, my close friends and family. I didn't want my son to get bullied at school because his mum was wobbly. I didn't want to have to explain if something happened, I didn't want to have to explain if I fell.'
(Suzie, 45-54)

One parent carer reported how she had felt offended when someone had spoken about her child's symptoms to her:

'She was diagnosed when she was 8. She had been having issues with her joints for a long while. The nursery nurse picked it up when she was three, she asked if she had something wrong with her knees. I took offence.'
(Jennifer, 55-64)

Thinking about the future

Other participants reported that their minds turned quickly to their future after they had been diagnosed and had begun to investigate the condition:

'When you read about the symptoms and what can happen, there was that thought of what the future would be like. Things like kids and family and not being able to do the things that you thought you would.' (Hari, 25-34)

Participants observed that thinking about and planning for the future was difficult in the context of a condition which varied significantly in its impact and was difficult to predict, and that this in turn could leave them uncertain about how to feel about it:

'The neurologist says everyone's template is different. It is progressive but people get different symptoms and it's difficult to compare.

I don't know how to feel about it, I can't get any certainty about the future, even if you haven't got ataxia you could go out and get hit by a bus. It isn't nice, but I don't worry about it too much.' (Danielle, 25-34)

'I asked the doctor, how long until I need a wheelchair. He said that he couldn't be certain.' (Liam, 35-44)

One participant made the point that thinking in too much detail about the future was difficult for anyone:

'I knew I was going to get worse and need a wheelchair. When you are young you don't think about getting old, just as now you don't really think about needing a wheelchair. I just thought that I would make the best of things.' (George, 65-74)

Participants who had seen other family members affected by the condition reported that their prior knowledge had meant that they knew what they were dealing with. However, this did not mean that the impact was easy to cope with:

'I feel settled in my own way of doing things. I look at my dad and I think that he kept working until he was 65, he is 70 now. Although he did give up driving in his 50s, he never liked it, so I hope that I can go a bit beyond that, that's my mentality. I do think about it, with my dad I have a sight of what is coming my way.' (Kate, 35-44)

'When I first displayed symptoms, I did know what it was. I had a strong family history of ataxia and grew up with my father having the illness. I still find it difficult to come to terms with it, and understand why it is happening to me though.' (Claire, 25-34)

Section 4: Impact of Ataxia on Daily Life.

Survey Responses

Health

- The survey provided clear evidence of the impact of ataxia on people's health.
- A significant minority of respondents, 43%, reported that their health was poor or very poor.
- 26% felt that their health was satisfactory, 17% that it was good.
- Only 11% reported that their health was very good, 3% that it was excellent.

Impact of Ataxia on Day to Day Life

- The survey provided very clear evidence of the significant impact of ataxia on people's day to day life, in particular on their mobility and ability to carry out day to day tasks, but also on their mental health and ability to take decisions.
- Over three quarters, 77%, of respondents felt that ataxia had at least a significant impact on their mobility, nearly 50% a very significant impact.
- 64% felt that it had had at least a significant impact on their ability to carry out basic physical tasks, 88% at least a somewhat significant impact.
- 39% felt that it had at least a significant impact on their mental health, 67% at least a somewhat significant impact. Around a third felt it had either a not very significant impact or no significant impact at all.
- Just over half, 51%, felt that ataxia had at least a somewhat significant impact on their ability to make decisions, just under half that it had either a not very significant or not at all significant impact.

Interviews/ Focus Groups

Participants explored:

- The impact of ataxia on their daily life, focusing on their mobility and their ability to carry out everyday tasks, and the cognitive impact of the condition.
- The impact of ataxia on their mental health, and their assessment of their general state of health.

Mobility and Travel

Mobility was consistently identified as being the most significant of the impacts of their condition. Different levels of impact were reported in line with the different stages of progression participants had reached, and the different types of ataxia affecting them.

Mobility impacts included:

- Not being able to walk far.
- Having to use a wheelchair within and outside the home.
- Cruising round the furniture for balance when within the home.
- Trouble maintaining balance when standing.
- Feeling dizzy without warning when standing or turning round.
- Experiencing falls.
- Not feeling comfortable walking outside the home.
- Feeling uncertain about using stairs, and not being able to go downstairs without holding onto a bannister.
- Having to sit down when getting dressed.

Participants also reported that their mobility varied day to day:

'Some days I can't get up at all, and I am stuck lying flat. On those days my husband has to carry me to the bathroom.' (Rachel, 45-54)

One participant who was still able to walk reflected on some of the challenges that she faced when she was out and about:

'I can't do steps very well. I don't go into town because the pavements are uneven. I would walk an extra mile to cross a road because I can't go down a kerb.' (Mary, 55-64)

Participants explored issues that they faced travelling. For a number of participants driving remained a possibility, as their ataxia had not yet impacted on their co-ordination. Others were not able to drive because of the extent of impact their condition was having, and of the medication they were taking.

Participants who were wheelchair users experienced a number of specific challenges. Travelling in a wheelchair was seen as difficult because of encountering steps, kerbs on pavements. Travel outside the home was seen as requiring planning ahead.

Using public transport was a significant challenge for many participants due to accessibility issues, participants point out difficulties with steps on trains and buses and in stations.

Mobility issues had broader life impacts for some participants, in particular on their ability to live independent lives, engage with other people, engage in loved activities, or on their confidence engaging in normal activities:

'I can only just walk on my own. This means that I don't really go out alone, so I am usually with my mother, sister, or an able bodied friend.' (Claire, 25-34)

'Ataxia makes it hard going up and down stairs. I have lost a lot of confidence going to the theatre or the cinema, I worry about whether or not there will be rails to hang on to.' (Suzie, 45-54)

'I don't like being in crowded places, I don't feel safe on my feet.' (Gary, 55-64).

'I can't travel to places by public transport, they aren't accessible. When I can get a lift I can go horseriding, I compete with Riding for the Disabled, and I can also link with Inclusion Scotland when I can get up to Glasgow and Edinburgh.....I feel stuck, I just feel stuck.' (Sian, 25-34)

Participants spoke of using a variety of mobility aids; wheelchairs, rollators, zimmers, walking sticks and mobility scooters. Participants were very conscious of the way that their use of different aids was increasing as their condition progressed, and of the way that aids they used under some circumstances would increasingly be what they would use under all. Acceptance of that could be difficult for some:

'I started using just one walking stick and a hiking stick, and I've now progressed to using two. I have a power chair for when I go for a large shop. I have a wheelchair provided for me which I use as a mobile chair in the house. I hope it will be some time before I have to use it all the time.' (George, 65-74)

People experienced issues with the wheelchairs that they were using, with the size and weight of the chairs consistently identified as being problematic:

'I have to use a wheelchair, my balance has deteriorated so much that I have to use the wheelchair in the home. I can't get it out of the door, and I can't get it into the car, it's too heavy. I have to resort to using a walker when it's outside.'
(Frank, 75 plus)

Speech

Participants regularly reported issues with their speech, with a number asking during interviews whether or not the interviewer felt that they had an issue with their speech, and whether or not the interviewer was able to understand them properly. Making themselves understood was a challenge for a number of participants when speaking to people outside the family:

'I do have an issue with my speech, it's a bit slurred. I am talking a bit slower with you so that you can understand me. I don't have to do that with my wife, she understands me.'
(Ray, 65-74)

Again, the progression in the impact of their condition on their speech was something participants were very aware of:

'It affects my speech. I know that it will deteriorate over time. I've been to an ataxia support group and there is a lady there with the same type of ataxia that I have. I find it difficult to understand her, I am not looking forward to that, I am speaking slowly to you now so that you can understand me.'
(George, 65-74)

Some participants felt that their speech was generally less affected by their condition, but reported that when they were tired it became worse.

Fatigue

After mobility and speech fatigue was identified as having the most significant impact on participants' lives, and their ability to carry out everyday tasks.

This impact could be seen in a number of different ways:

- Only being able to do a single shop, rather than visiting a number of shops.
- Not having the energy to keep up a job, or to conduct a social life.

One participant talked in detail about the impact of his condition, but also about how it could be hard to distinguish that impact from the impact of age:

'I am much more tired, though at 74 what should I expect. I find it difficult to say this is all caused by my illness. For me, it is difficult to accept that it might be my illness, I have had different experiences from the others [in the focus group]. I find it hard to do physical and mental work all day. If I've done half an hour I need to sit down.'
(Malik, 65-74)

One participant described the impact of her conditions on fatigue stressing both the severity of and fluctuations of that impact:

'It's episodic. When it hits I can't do anything, I have to lie down. It can come in seconds and it can be triggered by pain or the heat. I think that stress impacts on it, and I can struggle to sleep.'
(Petra, 45-54)

Everyday Tasks

Participants reported a number of other impacts on their ability to carry out everyday tasks:

- Not being able to grip and hold things.
- Dropping things, with picking them up also difficult.
- Finding it hard to focus on tasks.
- Feeling 'a bit shaky, like Parkinson's', and finding it hard to keep still.
- Not being able to write properly.
- Carrying drinks/ cups of tea/ a round of drinks when on a night out.
- Drinking from normal cups.
- Not being able to reach things that were up high within the house (reported by wheelchair users).
- Not being able to cook at all, because of not being able to reach stoves or handle heavy pots or pans safely, or finding it hard to cook alongside other family members, which for one participant had been a valued activity.
- Taking longer to carry out basic tasks such as having a shower.

Participants referred to the progressive impact of the condition on what they were able to do, and to the fluctuation of their capacities within the overall progression of the condition. These created their own challenges:

'You have to adapt to change all the time, over time I can do less and less. You are aware of this every day. There are things that you can't do all the time when you are having a bad day, you have good and bad days. Today is a good day.'
(Catriona, 25-34)

'It affects everything. Sometimes I can't do a little bit sometimes, I can't do a lot.'
(Liam, 35-44)

Some of these difficulties could have a wider social impact:

'Things like getting in a round of drinks at work and cups of tea in the office. I don't do them. I would just spill them. I don't want people to think I am rude and I don't want to embarrass myself.'
(Danielle, 25-34)

'I am not able to do a lot of things that you would hope or expect. There are things that I can't do with my nieces and nephews.'
(Liam, 35-44)

Several participants noted an impact on their ability to write, and that they were forced to rely on using keyboards or dictation instead. This could impact on simple things such as not being able to sign for packages being delivered to the house.

For a number of participants their ability to carry out basic household tasks had been maintained by aids and adaptations:

'I do all my bathing by myself. I have a wet room in the house, and there are handles in all the right places.'
(George, 65-74).

Some participants reported making significant changes to their everyday lives as a result of their ataxia. One had moved hundreds of miles from their initial home:

'The hospital said that we should try to make life less stressful. Life back in [area near London] was very stressful, so we decided to move out to [rural area in Wales].'
(Mary, 55-64)

Cognitive

Participants had different perspectives on whether ataxia impacted on them cognitively.

For some, there was no impact on their ability to think or make decisions.

Others reported that there was some impact, suggesting that their 'processing speed' had been reduced and they were not able to make decisions as quickly as they once had:

'I am not thinking as quickly as I once did. It's all going a bit slower, I think OK but it all takes longer to work out.' (Peter, 55-64)

Others were struggling verbally at times:

'Sometimes I can't find the right word. I know that happens to everyone, but it does happen more to people with ataxia.' (Hari, 25-34)

Some older participants were not certain whether the cognitive issues that they were experiencing related to their health condition, or whether they resulted from their age. One younger participant noticed that cognitively she was not performing as she had, but put this down to no longer being engaged in work or study, not interacting as much with people, and not being as active more generally.

One younger participant noted an impact on his cognitive ability, and therefore on his sense of who he was:

'It has had a cognitive impact. I was always considered bright and competent, but I've lost that sharpness of thought. I was at an appointment last week, and I was asked to look at a letter and come up with words. I was always good at scrabble, but I got stuck after 6,8, 10 words.' (Jimi, 45-54)

Impact on Health and Wellbeing

General/ Physical Health

Participants were consistently relatively positive about the state of their health in general, when setting the impact of ataxia aside. This sometimes seemed associated with having come to an acceptance of the impact of ataxia on their condition.

'I'm generally OK. I get tired easily and I'm not that active due to falling whenever I try to move about, but I feel healthy enough.' (Claire, 25-34)

'Paradoxically I'm probably the healthiest I've ever been. I've been a vegetarian for over 40 years and I eat and cook a lot of fresh food.' (William, 55-64)

Others reported experiencing other health issues alongside ataxia, such as heart conditions, COPD, bladder issues, and an enlarged prostate.

One participant also made the point that the impact of ataxia on their mobility could lead to negative impacts on their health:

'Ataxia only really damages my health when I fall over or bash my legs.' (Frank, 75 plus)

Mental health

Participants did raise more issues about the impact of their condition on their mental health. Ataxia was seen by many as something that they had constantly on their mind as they faced the challenge of everyday living.

The level of distress was significant for some participants, involving in some cases having what they described as a breakdown, in others having hospital treatment.

One carer spoke of his son having been on anti depressants for a number of years, and having experienced suicidal thoughts. Others had sought help with serious mental health problems:

'I had a nervous breakdown. I saw a therapist for a few months, and we discussed why this was happening, and what it meant for my future. I got prescribed anti depressants by my GP. I took them for over a year. I don't take anything or see anyone for my mental health now and am presently feeling OK. I still question why this is happening and how I don't have much of a future, but I am not depressed now.' (Claire, 25-34)

Negative impacts on mental health were identified as coming from reductions in people's ability to carry out everyday tasks, from the everyday reminder of the impact and progress of their condition, from the loss of future plans and dreams, from comparison of their lives with those of their peers, and from feeling as if they had less of a contribution to make to society:

'It's definitely dragged me down. That's thinking about the things that I can't do. It does affect my mood when I can't do some things. I feel less able to contribute and less valuable as a person. I worry that I am a burden.....

I worry about whether I can have a family. In terms of a relationship I worry about not messing someone around given that I have the condition, I worry about not being able to do the things that a father should be able to do with his kids.' (Hari, 25-34)

'I have had a lot of mental health issues as a result of my ataxia. There are a lot of things that you can't do and that affects your self worth. It's been a contributing factor to my depression, I struggle with my self worth, I've had a lot of therapy to deal with this.' (Liam, 35-44)

Others described their mental health in terms of it being up and down, and also highlighted how struggling to meet particular physical challenges could be a trigger for stress:

'My mental health is mixed. I have good days and bad days. There are moments when you think, I can live with this, there are moments when you think, fucking hell. Walking up the stairs for an appointment, I got breathless and my heart started racing, I felt like I couldn't breathe. It was just momentarily, but I thought to myself, my God, this is going to get worse.' (Jimi, 45-54)

One participant described the psychological impact of not being able to write properly:

'I can barely write. My right side is appalling, the pen can just jump out of my hand, I can't control my writing. That really upsets me, it is something that you

take for granted. My 9 year old son has beautiful handwriting and he tells me that it's better than mine and that hurts.' (Suzie, 45-54)

'Suzie' captured more broadly how she felt in what are the early to mid stages of the progression of her condition:

'My mental health and wellbeing are OK at the moment. I try to stay positive, but it's hard, it's not the brightest outlook. I don't think of the future too much, I live for today, what I can do today I will do today, I will do what I can tomorrow.' (Suzie, 45-54)

One participant raised the issue of feeling a sense of stigma as a result of being disabled:

'I feel conscious of saying to people that I don't work. I feel bad about it. But I feel sleepy half the day, and think I spend the other half explaining to people.' (Frances, 45-54)

There could be a contrast between someone's general feelings about their mental health, and their ability to deal with particular aspects of their life:

'My mental health is generally pretty good. I'm OK in myself dealing with everyday issues. I find it a strain sometimes to be calm and collected with other people, to cope with that. It does get me down a bit.' (James, 55-64)

One participant picked up on the seasonal impact of her condition on her mental health:

'This time of year in particular, it's not great for the way I feel. I find it difficult because it's quite an isolating condition. When it's cold and wet outside you can't get out of the house. In the Summer months I can take my daughter to schools on her bike and you meet people along the way.' (Frances, 45-54)

Not all participants were negative about their mental health. Some described themselves as being quite positive, with the impact of the support they received helping them psychologically as well as practically, although even those who were more positive referred to difficulties and frustrations.

However, even when participants felt that they were generally positive about their health, they could struggle psychologically with the impact of their condition on their life hopes:

'I am quite a positive person. If I was a negative person, I would be down in the dumps all the time. You do notice as you get older, with all your friends settling down and having families. Your mental health takes a beating and it affects your confidence.' (Catriona, 25-34)

Rarity of Condition

A number of participants discussed issues for their wellbeing resulting from the invisibility and/ or rarity of their condition.

For some, this had simply created frustration at having to explain their condition repeatedly to people who did not understand it. A number of participants had been seen as being drunk by other people. For two participants that had led them to

encounters with the police, with both being accused of having been drink or drug driving, although for one of them that had had the positive side effect of leading to their diagnosis.

One participant had taken another approach:

'I've had that issue of people sometimes thinking I am drunk. Having to explain that I have ataxia is too difficult. I lie about it and tell them that I have MS.'
(Gary, 55-64).

Care Needed.

Many of the participants were receiving care from family members, and some participants were providing care to family members. Family members delivering this care included people living with the person with ataxia as a partner, child or parent, or living elsewhere, with siblings and children often providing care involving basic household tasks.

The care provided by partners and parents could be intimate:

'My wife helps me with bathing and getting dressed. She helps me get dressed and have a shower in the morning.....she works part time at the [local hospital] She has to do everything for me, I can't even go to the shops.

In some situations the quality of the care that family members were able to offer was compromised by the health of the person offering the care.

There had been some challenges for some participants in having to rely on family members as their carer:

'My husband has taken over the cooking, though I still do it occasionally. I did it all when we had young children. He has taken on the housework. It's slipped a little as my mum would say, it's not up to my standards.'
(Rachel, 45-54)

Others were not able to access much help from their family because they lived a considerable distance from them, or because they had become estranged, or because other parts of the family were impacted by ataxia.

For some participants things had become more difficult since bereavement, with impacts on both mental health, and possibly on the progression of their condition:

'Things have sped up over the last four years since my husband died, and had become more stressful.'
(Mary, 55-64)

Other participants had help that they paid for such as cleaners, although some experienced difficulties accessing support from personal assistants:

'I do have a budget for personal assistants, but I can't get people at the moment, it's a rural area and they are hard to find.'
(Sian, 25-34)

One participant referred in some detail to the real support she received from a team of professionals, but also to the difficulties of asking for help:

'I have a very good team; an OT and a physio and a speech and language therapist. I can call on their help, but I don't really have anyone else in. I don't really accept my condition, I am very stubborn and not the sort of person to ask for help. My husband being with me all the time means that I don't have to ask for help, if he wasn't there I'd need to have external help.' (Rachel, 45-54)

One participant captured the value of the support that she received on her experience of her condition:

'Sometimes you start to do things and then you remember that you can't. You get halfway and then you need to get help. The support workers reduced the energy I need to do things, which gives me more energy for rest of the day.' (Nicola, 45-54)

Some participants did not feel as if they had reached the point of needing personal assistants, and preferred to rely on their family for help.

Section 5: Employment and Housing Impact of Ataxia.

Survey Responses

Employment Status

- The survey provided very strong evidence of the impact of ataxia on people's working lives.
- The vast majority of respondents, 86%, were not in work.
- Of the 14% in employment; half of those were employed full time, one third part time and one sixth were in self employment.
- Much larger numbers of respondents, 29%, reported that they were permanently off work because of a health condition. 4% were temporarily off work because of a health condition.
- 42% of respondents reported being retired, reflecting the age profile of respondents.
- 9% referred to themselves as being unemployed, implying that they were not in work but still seeking employment.
- 70% reported that the impact of ataxia on their ability to work was at least significant, 78% that is was at least somewhat significant. This still leaves a significant minority of respondents for whom ataxia had not impacted on their ability to work.
- Ataxia has not been a lifelong barrier to work for the vast majority of people responding. 90% of respondents reported having been in employment at some point, only 10% had not.
- 76% of those who had never worked had been diagnosed before the age of 18, half of those diagnosed under 18 had never worked.

Interviews/ Focus Groups

Loss of Employment

Many participants had stopped working because of their condition. Examples included:

- A hotel manager stopping working because of the impact on his speech and therefore on his ability to engage with people.
- A carer who kept getting attacks associated with her ataxia and finding herself with work piling up as a consequence, who had lost a number of jobs and had reached the point of feeling that she couldn't tell people about her condition.
- An HGV driver who had found that he could not get up the steps into the cabin of his lorry.
- A nurse who felt she was no longer quick enough on her feet and crutches to keep up with patients, and who had not fitted in to a more desk based position which she had lost (although that had not been the result of her ataxia.)
- A warehouse worker not being able to get on and off forklift trucks and finding walking and going up steps within the warehouse difficult.

Many of these participants felt that they would still have been in work had they not had the condition. Some participants, even in their early seventies, felt that they would otherwise still be working. Other, younger, participants felt that they would have turned, and would still like to turn to something else:

'I worked until I was 24. I was an animal carer back in County Durham. My contract ended, it was only short term thing, nothing to do with ataxia. I would have stopped working by now because of the symptoms, I would like to do something with business or computers.' (Sian, 25-34)

For some participants, reasonable adjustments at work had not been possible, and alternative employment with their employer had not available. Others had gone through the process of their employer trying to make adjustments on their behalf:

'They did as much as they could do with reasonable adjustments. There was not real procedure at work to retire early, so I had to go off on the sick. It was a worry at the time, I wasn't in the support group for ESA so things were a bit up in the air.' (Nicola, 45-54).

'I had to give up work [one of two jobs] quite quickly because of falls. It wasn't said, but it was implied that I might fall on the children. I also taught football to preschool kids. I had to take up an admin role, but that's not what I was employed for. My strength went quite quickly. I had issues dropping and carrying things like files.' (Rachel, 45-54)

Some participants had retired on the grounds of risks to the safety of others. One described how his GP had told him he would not be safe on a building site. 'Wayne' who had been a lorry driver captured how the condition would have impacted on the safety of those around him had he continued to work:

'I still drive my own car, but my tiredness worried me when I was working. I gave up straight away [on diagnosis], I didn't want it on my conscience, driving a 32 tonne lorry and killing some innocent kid and their family.' (Wayne, 55-64)

For some participants other events were as important in their loss of employment as ataxia, for example the closing of the company they had worked for, broader redundancies within the organisation or simply the end of their contract. However, these participants generally felt that the impact of ataxia had been to inhibit their ability to get further employment.

Some participants identified other health and life issues as being more or as important than ataxia in impacting on their work situation:

'I retired because of my health, mostly down to that. A lot of things were happening, my back was getting worse. I had risen up the ranks at that point, I didn't have to code any more, so it had less impact on what I had to do, though my typing was more erratic, and some days were better than others.' (Patrick, 65-74).

Limited Experience of Work

Two participants had experienced very long term unemployment, one had never been able to work despite having good educational qualifications:

'I last worked in the 80s. My ataxia and some other health conditions [stopped me from working]. Doctors told me now to work and do the lifting because of my tiredness, and my co-ordination was also affected.' (Gary, 55-64).

'She has undergraduate and post graduate degrees in business, we were able to cope because we drove her everywhere. Work would be very difficult because it takes 2 hours to get ready in the morning.' (Jennifer, 55-64)

One participant had only briefly taken paid employment, despite having a masters degree, something he put down not only to his condition but also to entering the labour

market in the post recession period and to losing heart after consistent rejections. He had however, engaged in other activities:

'I've done volunteering since then, with the CAB and the RSPB, and I've done a lot of writing. I have been trying to get stories published, I've been writing for the last 4/5 years and I've had three published in the last three months in magazines. When I finished my degree it was the recession and I couldn't find anything, I wasn't getting much interest. I'd been looking for 10 years and I thought that's enough. There have been opportunities for admin work, but I'd rather do my own admin and focus on the writing.' (Liam, 35-44)

'Liam' also reflected on the experience of being a student with ataxia:

'I thought that I could do a degree and no one would notice. That wasn't a great idea. That went well, it would have gone better if I'd told people about my ataxia.'

Financial Worries

Participants were often very worried about their financial situation, which could leave them in a difficult situation, working when they no longer wished to be:

'My anxiety was sky high. It was about a year and a half that I was finding it [work] difficult. The last six months were a real struggle. It was both money and because I wanted to keep going. I was very anxious, I'd been working for 30 years and was anxious about the benefit system.' (James, 55-64)

'James' had experienced this anxiety despite feeling that his employer had treated him well, although it could not give him all the assistance that he felt he might have needed:

'The company was really good. They have me sick pay of a couple of hundred pounds for six months. They were very reasonable. I was well treated, there were no other jobs I could do there, there were no adjustments that they could make.. I didn't really get advice from them, they were more interested in my symptoms. I really felt there was nowhere to go for advice.'

'Graeme' had received some limited support from his company which he had found helpful:

'The company gave me some advice. They helped me out with some things. They told me about DLA and ESA and they pointed me in the right direction. They helped out at the start, and then I went to the CAB.'

However few others had received much support at the time from their employers, or from anyone else, to deal with their situation:

'I didn't get advice or help from anyone at the time. I packed up on health grounds and the company understood that, but they were no real help. I worked for the company for three years, and had done the same stuff for a few others, they understood they had to give up, but there wasn't much they could do.' (Peter, 55-64)

Participants often missed work for more than financial reasons. Similarly, others were clear that they had continued work after the onset of their condition because they had wanted to stay active/ feel they were making a contribution:

'I haven't looked for another job, I felt that I should stop. I don't think that was a wise decision, I think you should work. The job was part time, but it was so good. Meeting lots of people and talking all the time was so good for my ataxia.'
(Catriona, 25-34)

'I hung on for as long I could. It was both concern about money and wanting to be able to work for as long as I could that kept me going.' (Graeme, 55-64).

The timing of retirement and being aware of the financial issues going from part time to full time could be a critical issue:

'The issue for me around retirement was if I had gone with a part time rather than a full time salary it would have been a struggle for me. Reasonable adjustments and part time work would actually have been unhelpful. I would have been financially disadvantaged.' (Alex, 35-44)

'Alex' recognised her good fortune:

'I had no regrets about retirement, non whatsoever. I hadn't realised how much I was struggling at work. I'm sad that other people don't have that opportunity. It's not about extravagance, but about the mortgage.'

'William' had also been protected from financial concerns:

'I wasn't worried about money. At the time I had a large flat in London which I sold to come back to Glasgow and be near my family.' (William, 55-64)

Negative experiences losing and seeking jobs

Giving up working work could be a very negative experience. This could be the case whether or not participants were worried about their money situation. 'Sandra' had given up her job in a hospital as she was struggling when moving around:

'They made me go off on the sick. It was a horrible experience, an angry and bitter process. That thing of being told I was not fit for work, that I was sick..... Money wasn't really part of the worry for us, we had always rubbed along OK and were able to keep going.' (Sandra, 55-64)

Leaving work had been a protracted process for another NHS employee:

'The process of retirement wasn't straightforward, the BMA got involved. The NHS were initially not supportive. I started off going to occupational health because I was struggling. My doctor recommended that I drop the inpatient work. The line manager felt that didn't fit with what the service needed.

People hadn't heard of ataxia, I found myself having to explain that it was progressive. The adviser at the BMA said to look at my pension. There was an issues with part time, I was having problems walking and with other tasks. I went off with stress because of that. I just didn't go back. Eventually I got things understood by my line managers and they were supportive. Perhaps that had been their aim all along.' (Alex, 35-44)

One participant highlighted a set of negative experiences, initially poor treatment from her employer, and then by a prospective employer when looking for work which had left her demoralised and no longer seeking work:

'I haven't worked for about 8 years. I used to work with vulnerable people.....I finished after I was filling out a form for a client and my handwriting was big on it because of my ataxia. I explained to my manager that that was why and it seemed to go in one ear and out of another. I decided to leave, a lot of people were shocked at the manager's attitude.....

I tried to get another job after that. That was on the other side of London. When I turned up with a walking stick they said I had got the wrong date and time. It was lucky I still had the e mail. It showed I was right. They had to apologise....After that I didn't want to go for another job because of my mental health.' (Melanie, 45-54)

'Petra' focused on the psychological impact of losing work:

'I was sacked from a few jobs because of my condition. I thought I couldn't tell people about it. It has had a big impact on my life. I couldn't go out of the house sometimes. I felt I was being judged. I have been really distraught about it for years. I couldn't look after people any more, there are a lot of people that judge you.' (Petra , 45-54)

Other participants highlighted the difficulties they faced/ would face if they sought employment, both in terms of employer attitudes and practical challenges:

'I have tried looking for work other jobs, but people see me with the stick and even though they are not supposed to, they ask me what the issue is, and when I say I am disabled they find someone else. They would know they couldn't rely on me.' (Rachel, 45-54)

'At the time I was made redundant I had a really sore hip. It made getting in and out of the car difficult, I felt I needed to get it fixed. That was a couple of years ago, now I've stopped driving..... I just think, if I did get a job, how could I get there. Stuff has come up, but I am really lazy and I am just making excuses. I should be doing volunteering, I should at least do that. It would be nice to have some money in my pocket, I would like to work 12 till 5, but that's probably not possible.' (Catriona, 25-34)

Participants Still in Work

A number of participants were still working.

Some noted the impact of ataxia on the way of working, but felt that this was something that they could cope with:

'I get around in a 2 door car. Organisation is an issue for me, but I have my own way of doing things, which works for me, it wouldn't for anyone else. I feel settled in my way of doing things.' (Kate, 35-44)

One participant that though now retired through age, she had been able to continue in her work despite her condition because no one at her employer had either noticed or been concerned by the situation:

'I didn't have to retire early [from work at a school]. I was walking badly and my speech was slurring but no one seemed to pick up on it, so I carried on.' (Anne, 75 plus)

Others, whilst coping, saw there as being impacts on their ability to cope, and on their ability to progress, sometimes in obvious ways, sometimes more subtly:

'It's hard to focus on a computer screen. Things take me longer. Walking and talking and chatting around the office is not as easy as it should be. I can't do the social side as easily. I do have issues on the phone sometimes. I think I will have a shorter working life, I won't be able to get to the point that I would have if I hadn't had the condition. It affects your ability to build the relationships that you should have with people.' (Hari, 25-34)

One participant was very clear about the impact that his condition was having on his professional prospects, a situation he saw as likely to head in an unplanned for negative direction, despite his employer attempting to help:

'Before my health issues I was on the verge of promotion. Now it's all changed and I might be looking at demotion. It has had an impact on my cognitive skills....'

Work have been really supportive, but they can't continue with my objectives not being met. They are proceeding in accordance with the advice from my neurologist, but there are real issues about whether I can keep doing my job. One option would be to take a demotion to something less stressful and demanding. It would mean a pay cut though. I have gone from being someone who had an expansive career, to someone who will need to take a step back.' (Jimi, 45-54)

'Jimi' was clear that he needed some help in the situation in which he found himself, which was worsened by broader financial difficulties:

'I would like a package of specialist external support and some kind of financial advice.'

He was also clear that he was continuing with his current work because of his financial situation, and his preference would be to step down his hours if his financial situation allowed it, in particular, if his insurance policy paid out:

'The ideal scenario would be if my insurance could pay off my mortgage and leave me with something to live off. That would mean I could work three days a week which would keep me active. I could use the time to be a father. You could deal with the emotional and mental things you want from life as well. At the moment I am exhausted when I get to spend time with my kids. I'm not forced to, but I do go into London for work and it takes me hours.'

Some participants who were in work felt that their choice of work had been restricted, or that they had not been able to supplement their current income with other work:

'Because of that lack of muscle co-ordination and balance, it's a hindrance if I am trying to do waitressing or jobs like that, which would be great if I wanted to do the odd weekend and evening shift when you aren't doing your own job.' (Danielle, 25-34).

A number of older participants were active in paid or voluntary sector roles but felt that their ability to work had been curtailed before its time by the impact of their condition or other health issues:

'I'm struggling to get to meetings these days. I definitely can't work as much as I did, so it does have an impact on my finances. I can't get involved in meetings, I used to work across London, and now I can't get to places unless I get dropped off on the doorstep, public transport is a no no.' (Frank, 75 plus)

'I was moving to retirement anyway, so I didn't have to retire earlier, but I was looking to do more voluntary work. About 2 years ago I had 12 voluntary roles, then I was struck by [other condition]. I had to give most of them up, I'm now down to 2. My condition doesn't really affect me in those. I am fine with voluntary work, paid work would be another thing, I'd be very much more worried about not being able to fulfil.' (George, 65-74)

Others felt that their work had been impacted more by broader changes in their field than by ataxia itself:

'I am still working as an architect, but that is slowing down. It's not so much about my choice or the ataxia, it feels like the way the profession is going.' (Ray, 65-74)

One participant described in detail a very difficult situation with her employer which had led her to ponder whether she would be forced to give up work:

'Work are being awful. I am taking myself away from that at the moment. I feel that they are putting too much pressure on me in the circumstances. I told them about the diagnosis, their words were lovely, they said they would do anything to help. They would find an OT to help. Their words were absolutely great, their actions were crap.

I am a in a team of 8, there are seven of them in the one building, and I am in the other. It used to be 5 in that building, 3 in mine, but one left, and the other person moved when I was on holiday. I can't get to the other building, it has steps. I feel that they could split things, but they won't.

They have been bought out by a big national company, it feels as if they are not individuals, they are just numbers.

I don't think that they understand what ataxia is. They said they will get an OT in to help, they organised a meeting with the OT, but I had to travel into Leeds by taxi into a massive building and find my way around.

The OT had the wrong information, he thought that I had been off work for months. I felt that they were covering themselves and not helping me out. There has been nothing happened with the OT, he said I was very resilient and had not let the ataxia affect her. They got the report and nothing happened. No one looked at implementing it to help my daily life. They didn't even try to understand the problem and think about how they could help.

I am not going back there, it is a toxic environment, they have told me they are watching me, they have been through my e mails with a toothcomb.

I have been there a long time and they have paid me very well, but I think it would be easier for them if I was not there. They would be able to go out of the other building and wouldn't have to worry if I wasn't there.' (Suzie, 45-54)

'Suzie' was also worried about not being able to get a job if she gave up this one, and had some concerns about her financial situation in the longer term, which she feared might stop her from making a clean break:

'Who else will employ me? I know that it shouldn't but you can bet your bottom dollar that it will affect my chances of getting a job.....

Our finances are OK at the moment, I've only been off for a week. I'm not sure what they are going to do. If I'm not working, I won't get paid but I can't put myself in that environment, I've been dreaming every night about work, I'm constantly worrying at weekends. My husband is an MD, but the loss of a salary is still the loss of a salary.'

One participant felt that she was largely unaffected by ataxia when working, and that staying at work was important for her:

'I have been working at Tesco for 16 years and will go on for a few years yet. When I am sitting down, you wouldn't know that I have a problem. I have to be able to work to live. It's also the social side. I have no neighbours and there are no footpaths. It's quite isolated. As long as I can drive, I intend to work.'
(Mary, 55-64)

'Mary's' experience with her employer had not been without difficulty, but it had been much more positive than Suzie's:

'Until a few years ago ataxia wasn't recognised. They didn't know anything about it at work. They do now. I talked to them and they went away and researched it. They had to make sure that I have the right degree of support if I needed it. The staff and the managers didn't know before that. It's not like multiple sclerosis which is something that is instantly recognisable.'

Caring Responsibilities

A number of participants had given up work to care for partners or children, or reported that their partners had given up work on their behalf.

In some cases there had been a double blow to employment in the household:

'I had to give up work when 'Tracey' was sectioned, I was doing well paid work on the railway. She used to work as well, she was a domestic carer and cared for her mother.' (Gareth, 55-64)

'My husband had to give up work to look after me. It was the downturn too.'
(Rachel, 45-54)

Some participants with caring responsibilities had reduced their hours having found working full time impossible, even when they had attempted to work flexibly. This could cause significant financial worry in difficult situations:

'I tried working for a couple of months full time after it happened [an accident to his wife leaving her unable to look after their child with ataxia.] Then I went to flexibly working, 4 days in [place of work] and one at home, but it was too difficult.

I was worried about money at the time. I was worried but I was forced to do it. It's life, you can't do too much about it. I could stay working or I could lose my wife. She was depressed and under a lot of pressure.' (Hamed, 45-54)

Housing

Interviews and focus groups did not focus on people's experiences of housing issues, but a small number of people highlighted the significant problems they were experiencing accessing suitable housing, problems that could impact on their psychological and physical health.

These problems could be driven by the financial impact of ataxia, 'Hamed' had seen his income reduce because he had taken up responsibility for caring for his children and reduced his hours as a consequence:

'I can't get a mortgage and it is very difficult to get a house. Before [when he was working] I would have done. It's more and more difficult to move Mohammed. That means money is on my mind all the time. If I had enough money I would be able to buy a house. I might be able to get a house that was actually accessible and suitable for my children's needs. If you have a new home it might be too small, but an older home might be bigger and would need a lot of adjustment and renovation.

It impacts on us all the time. It's when you see you son fall and hit his head on the radiator and there is a lot of blood. Then you worry that this isn't a life for him. He fell at night because he didn't want to wake us.' (Hamed, 45-54)

Like 'Hamed' 'Petra' was trapped financially in unsuitable accommodation:

'I am in a shared ownership property. It has been a real struggle. I have a real issues with my home. I can't do stairs but I can't move because it's shared ownership. There are a lot of stairs, I don't know where I can go with this.'

Other participants had been more fortunate and had been rehoused after their condition had worsened.

Some participants were beginning to think about the possibility of moving home, but were not sure about their next move, and were facing potential financial barriers and/or knowledge barriers to making that move:

'I have been talking to my PA about how my flat is not suitable for a wheelchair, I would like to move somewhere else next Summer. I'm worried about getting a new mortgage because I have a CCJ against me.'
(Melanie, 45-54)

'At the moment I am staying at home. But I'm 32 and I don't want to live with my parents until I'm 40. They have an extension, so it's quite a big house, and they work, so I have the run of it.

Money is not the first barrier to moving out, but it is a barrier. It's really that I don't have the information, that lack of information is the main barrier. Maybe if I could get a council house in the area. I don't really know much about council housing,' (Catriona, 25-34)

'There is now the issue of having access on two floors as I get older. We had planned for things, but now my ataxia gives me a problem with being in a two storey home. I am constantly thinking about it. We may need to move.'
(Malik, 65-74)

Section 6: Financial Situation.

Survey Responses

Overall Financial Situation

- Respondents reported facing a slightly higher level of financial difficulty than the general population.
- The Scottish Household Survey question was used in the survey to provide comparator figures to the general population to reflect the immediate focus of the research. Scottish data on household financial situations also broadly aligns with that of the UK as a whole¹.
- 42% of respondents felt their household was managing well financially, a lower than the equivalent figure in the general population (55% in the Scottish Household Survey.)
- 46% felt that their household was just getting by, slightly higher than the equivalent figure in the general population (35% in the Scottish Household Survey.)
- A small but notable minority suggested that their household was struggling:
 - 9% felt that their household was not managing well (8% in the Scottish Household Survey.)
 - 3% felt that their household was in deep financial trouble (1% in the Scottish Household Survey.)

Experience of Financial Difficulties

- Respondents who had experienced financial struggles were asked about how serious those struggles had been.
- Of the 12% who were not managing well or were in deep financial trouble:
 - Over half had used local authority crisis funds, around 6-7% of the total respondents.
 - 6 in 10 had used a foodbank, and 6 in 10 had gone without food because of financial pressure, about 7% of the total respondents.
 - 8 in 10 had gone without heating because of financial pressure, about 10% of the total respondents.
- For a small minority of respondents, financial troubles had therefore reached the point of significant crisis, with the prevalence of such crises amongst respondents exceeding the rate of destitution in the general population.

Impact of Ataxia on Financial Situations

- Respondents were asked about the extent to which they felt that ataxia had impacted on their financial situation, and the extent to which they were able to cope with additional costs directly attributable to ataxia.
- Just under half, 48% of respondents reported that the impact of ataxia on their finances had been at least significant, 68% that it had been at least somewhat significant.
- Respondents reported a spread of experiences in terms of being able to afford the equipment that they needed to live their lives with ataxia, with the vast majority, 78%, finding the cost at least something of a challenge:
 - 22% felt that they could buy all the equipment they needed without it being a financial burden.
 - 20% reported that they could afford all the equipment they needed, but that its cost was a burden on them.

¹ Scottish Government [accessed online at gov.scot], [Scottish Household Survey 2018](#), 2019

- 22% reported that they could not afford some of the equipment they needed.
- 22% reported that they could only afford a limited amount of the equipment they needed.
- 14% reported that they could not afford any of the equipment they needed.

Access to Informal Financial Help

- The survey explored respondents' access to informal sources of financial help from friends or families.
- Such support was accessed by a significant minority of respondents, 31%.
- 69% of respondents did not receive any regular financial help from friends or family members.
- 8% reported that they got help from parents they lived with, 6% from parents they did not live with.
- 12% reported that they got help from other family members, 6% from other family members they did not live with.
- 4% got help from friends.

Interviews and Focus Groups

Interviews and focus groups explored participants' perspectives on their financial situations.

Income Shock/ Level of Comfort.

A majority of participants reported that they had lost income because of the impact of ataxia. For many this had been a shock, and a significant change in circumstances:

'My income has fallen dramatically. I could earn a reasonable living in my job, and now my income has gone down. Money was never really a problem, and now it is.' (James, 55-64)

The shock of loss of income could be doubled when a partner gave up work to act as a carer:

'It's a big shock going from being on a salary to being on benefits. Our money situation is reasonable but it could be better. My partner isn't working any more, she looks after me. It was a dramatic loss of income, we had to rethink everything.' (Graeme, 55-64)

In contrast, a number of participants felt that their financial situation was reasonable, even whilst highlighting that they had suffered a significant reduction in income when they had lost employment.

Older participants, who had experienced less or no loss of employment due to ataxia, and therefore no loss of income, often described themselves as being in comfortable financial situations.

Many older participants talked in terms of the ataxia being a side issue to their more general retirement financial situation:

'I've put money aside with my wife. We are careful but we've always been careful. You need to talk about how long you have to communicate when you make decisions about spending. I worry about money in so far as I have to think

about buying a car and about my next holiday. We are comfortable but we have to be careful. I am more conscious about money, but I think that's an age related think and not an ataxia thing.' (Ray, 65-74)

Other older participants were in a less affluent situation, although one which they were still managing:

'I am reasonably comfortable. With my state pension and Attendance Allowance, I am getting the money that I hoped for. I have never been capital rich. I think that I would be under the Pension Credit threshold. If you can realise what the state provides you can survive. Your expenditure does come down when you retire, I am not going on foreign holidays anymore, getting on and off planes, I can't be arsed.' (George, 65-74)

Older participants were not immune from other events/ risks:

'I would day that we would have been in a very good position. We have downsized and we live in a house that we own. Then other things happened, and we had to use our savings.' (Malik, 65-74)

A number of participants drew a contrast between their situation, which they felt was reasonable but restricted, and shared by many people with and without ataxia, and the tougher situations that they felt some people were affected by/ the tougher choices that they faced:

'Our money situation is OK. We don't have to choose between eating and heating, but there are other things that we would like to do such as go on holiday. We have been impacted by the loss of income, but with normal living things are OK, I can't say they are that bad there.' (Hamed, 45-54)

'The loss of money does impact on the family. Not to the extent that it impacts on other people. We generally have enough. It has affected us, but you cut your cloth to fit your means. I would say that we are doing OK, we are not using foodbanks or anything like that, but we need to watch our spending. We are alright, but we are really cutting back on this and that and the other like everybody else. Everyone is worried about money, I don't think we worry more than the average person about the stuff we have. I know that there is always someone worse off than I am, there is always someone worse off.'
(Frances, 45-54)

'[Her husband] has a pension from 35 years working at the council. I only have the state pension, 'Sophie' is getting PIP and ESA. We are reasonably off, though we are worse off than we would be, but other people with ataxia are worse off again.' (Jennifer, 55-64)

One participant reported how tight his financial situation had become:

'I get all my direct debits out. I didn't have a tenner to make sure that one could be paid the other day. Only being able to spend £30 in a shop, that feels awful.'
(Gareth, 55-64)

Not all participants had experienced or expected to experience income shocks. Two who were had been on lower incomes for the longer term saw low or little impact.

One felt that their situation was not greatly altered by taking on caring responsibilities for their children, and that they did not expect it to alter much if they became symptomatic themselves:

'It wouldn't really impact on our finances if I gave up work. We have five children so our financial situation has never been great. We are lucky we have no mortgage and we have always lived frugally. We just cope with things, though I suppose we are below the poverty line at the moment.'
(Rebecca, 45-54)

One participant who had been out of work for over thirty years suggested that things had sometimes got financially difficult for him, worsened by welfare reform, but clearly a struggle across the longer term:

'Things aren't great financially, particularly when going through the process of going from PIP to DLA. Sometimes things can be worse than getting by. They can be a real struggle.' (Gary, 55-64)

Adjustment of Expectations and Lifestyles

It was also clear that many participants had coped with their situation by adjusting their expectations to the money that they had available:

'I was able to get benefits. Without that help I would have had to make difficult decisions about whether to heat or eat. I live like a student, very frugally, and my partner is in work, which is a help.' (Melanie, 45-54)

'I do OK financially, though I live frugally. My living expenses are at the lower end, but for a single person I do OK. If I had dependents it would be different, I would struggle if I was not single.' (Liam, 35-44)

'I cope OK. I live very simply. I don't drink, I don't smoke, I don't do anything apart from meeting friends for lunch or a coffee, I live very modestly within my means.' (Anne, 75 plus)

Being able to stay in work left some participants in a better financial situation, although again, the modesty of their aspirations was striking:

'We are fine, we manage to live comfortably. We have occasional holidays and I manage to save some money each month.' (Simon, 45-54)

Protective Role of Benefits

Benefits had a critical role in protecting people against the worst consequences of income loss both for people living in households with no one working, and for people where one member of the household was still working:

'My benefits pay for the bills. My wife's money pays for food. We do get by, but we don't live in luxury. We are not buying new sofas or anything like that, we get by and no more.' (James, 55-64)

They also played a role in supporting the incomes of people who were still in work:

'I am generally OK. My bills are not very high because I live alone. The living allowance part of my PIP is a few hundred pounds and that helps towards my outgoings.' (Claire, 25-34)

For one participant, his financial situation, based on claiming benefits and a small amount of income from an online business was better than it had been prior to the impact of ataxia:

'I get PIP and ESA, we are not well off but we are coping quite well. I managed to get my wife onto Carers Allowance. We are OK, now and again we struggle, we are alright until the damn bills come in. I do worry now and again. I have built up money with my online business, so I feel better off than I did when I was working.' (Wayne, 55-64)

The loss of benefits, in the latter case below due to the impact of welfare reform could also leave people in more difficult financial situations, with some participants, even over retirement age, struggling because of the impact of welfare reform:

'About 2 years ago they stopped paying an allowance to cover my mortgage. I had always got that. That's £200 a month I have to find now. I have to cut back on a lot of things.' (Anne, 75 plus)

'Money wasn't an issue, then Job Centre Plus said I wasn't entitled to sickness benefit. They said that I could work but that I couldn't do any job they sent me for, so I didn't fit any criteria. They withheld money from me for 6 months.' (Sian, 25-34)

'James' suggested that entitlements around Carers Allowance created some financial difficulties for him and his wife:

'My wife does about 20 hours work, she can't cut them, we can't afford her to do that. She can't get Carers Allowance. She would have to cut her hours substantially to do that.' (James, 55-64)

Informal/ Family Support

Few participants mentioned getting regular financial help from families. This was sometimes as a result of not having family that could help, or being estranged from families, but it could also be a matter of choice.

'Liam' captured this choice, and also the sense from many participants that family help was received in other ways, although he also acknowledged that his family would stand behind him if needed:

'I've not really had financial help from my family. I would love to be as independent as possible. They help a lot but not financially, the financial help is not as important as the help in other ways..... I could get help if I wanted.' (Liam, 35-44)

There were some participants who had been closer to very significant financial difficulties, and had been saved by the support of family members:

'For a few months I had nothing coming in because of the issue with my benefits. Now I'm getting working tax credit which helps me. Mum and dad helped me with bills when I had nothing coming in. I had enough to pay my bills, to keep the bills off my back, it was about four months.' (Fraser, 35-44)

Participants were very aware in some cases of their reliance on the income of other members of the family and their ability to share household costs to keep their head above water financially:

'We have enough money coming in. If my mum wasn't with me, I would struggle. Two of us here makes a difference, if it was just me I would really struggle.' (Sian, 25-34)

Families could be a source of help in other ways, for example through providing inheritances:

'I have been the beneficiary of probate, my step father left me a fair amount of money when he passed away. That money is important now, it accounts for about half of my outgoings. When that money runs out, I will fall back on the state.' (Patrick, 65-74).

Friends were a regular source of very low level support in kind in social situations for some participants:

'I don't get any money from my family. I have some friends that treat me when I'm out, they give me bits of food and things.' (Peter, 55-64).

Other Financial Buffers

Participants were also protected by occupational pensions that they held, or by insurance products:

'Our situation is OK, because of my police pension and 'Sandra's' NHS pension. Without those public sector pensions we would be in dire straits, the money wouldn't have been enough.' (Kenneth, 55-64)

'I had bought my house before I was diagnosed. I can pay the mortgage fine, I had critical illness cover with my mortgage.' (Fraser, 35-44)

Some participants affected by ataxia in later middle age were relieved about earlier financial decisions they had coincidentally taken to pay off their mortgage, or were in a fortunate position with housing costs:

'My husband and I paid off our mortgage ten years ago. We worked our socks off thank goodness. We don't have that burden, but it will still affect us not having that many come in any more.' (Suzie, 45-54)

'The house was bought by a trust set up when my father in law died. We live there rent free until I and my wife die.' (Simon, 45-54)

Some participants had made use of personal savings but were concerned that these would not last for ever. 'Rachel' was also clear that the impact of ataxia on the situation of her and husband had also been felt by their children:

'We make ends meet, but we hardly have any money left at the end of the month. We managed to save money because of his work, but our savings are going down. Sometimes I do worry about money because neither of us are working and our savings are going down....

Our older child has had to fund himself through university by working, we have not been able to help him, he has paid his own way through.' (Rachel, 45-54)

One participant referred to being reliant on the money that he had realised from the sale of a house:

'Everything seems OK, But I am going through money like water. I had to sell my flat to get some money, I now live with my mother. I am not worrying about it at the moment.' (Warren, 45-54)

Some participants were still dealing with the consequences of past financial decisions:

'I am not doing well financially. I still have student debt. I went to uni so I still have that hanging over me. I think that's common for students.'
(Danielle, 25-34)

Another participant felt as if she was able to manage on the benefits that she received but only due to her savings and to contributions from her ex husband:

'I feel as if I have enough money coming in to do what I need to in life. I've got some money squirrelled away, some money in trust so that it isn't looked at for benefits. I am worse off than I would be without ataxia, I should really have got a real job, but I never actually did. I only had a series of part time jobs when I was employed.....When I got money in from other sources, I spend it so that I don't get caught with it.' (Nicola, 45-54).

Worries About Money

The majority of participants felt that they did not worry too much about money. In some cases this felt like a conscious choice to avoid negative thinking:

'I don't really worry about money, I try not to think about it. I think you have a problem if you overthink things.' (Sian, 25-34)

In other cases, participants put it down to their personalities:

'I manage to hold my own financially. I only have my low wage and the money off the council tax. That's not an awful lot of money. I do worry a bit about running out of money and not being able to have the things I used to have. But I don't worry a great deal, I'm fairly level headed about things like that.'
(Mary, 55-64)

For other participants, concerns about money had become a feature of their life since ataxia had impacted on their family in a way that had not been the case before:

'I do worry about money, and I was never thinking too much about it before.'
(Hamed, 45-54)

'It's a constant worry, money. Thinking you could do with this or that, and then worrying about the fridge or washing maxhine breaking down. It does affect my mental health a bit. I'm anxious about it.' (James, 55-64)

One participant was clear about how this extra concern has changed his behaviour:

'It [loss of job] has had a real impact on my financial situation. I now look at my account every day.' (Martin, 45-54).

For some, this concern had reached the point of not being certain about their ability to meet their own basic needs, for others concerns were about particular payments that they had to make:

'I do worry about money. I don't want to run out of money. I worry about not having the money I need for food.' (Petra, 45-54)

'I am a bit concerned about the last payment for the car that is coming up, I don't really know how that will pan out.' (Liam, 35-44)

One participant was very nervous about financial commitments in the medium term in the context of potentially having to take a lower paid job and / or reduce hours, in particular about additional mortgage payments:

'One of the issues is that we took out another mortgage out to do the extension just prior to me getting diagnosed. We have a two fold mortgage now. It was bad luck we made that decision. I still have a big chunk of it to pay off..... Financially at the moment things are OK, but I haven't had to take a pay cut yet. We took out the mortgage on the basis of the affordability from what I was getting. It's affordable at the moment, right now it's difficult but manageable. It's the prospect of taking a pay cut or a demotion and in the long term my wife giving up work to look after me? We have that debt which will be difficult to pay if my circumstances change.' (Jimi, 45-54)

'Jimi' also expressed worries about his long term finances as did 'Hari':

'What happens with my boys who are 8 and 12, and there is still a long time ahead of providing financial and parental support for them?' (Jimi, 45-54)

'I worry if I am going to be needing bits of spending. I don't know what will happen to my salary. I am worried about saving for the future. I don't want to be reliant on the government. Will I be in work? Will I need care? I am not sure about my earning power, I may be saving less than I should be.' (Hari, 25-34)

Some felt that they lacked the control that they had once had over their finances and were concerned that this would have long term impacts:

'I think my savings will last about 10 years. When I do worry it's about trying to control things. I don't know why I am spending so much, I have never been profligate.' (Patrick, 65-74)

Short and long term worries about money could impact on participants' mental health:

'I don't really worry too much about my finances right now. I'm just worried that I won't have enough money when I eventually have to give up work and won't have enough money to cover my bills and outgoings. That does have an impact on my mental health, but less now that I am receiving help/ treatment for it.' (Claire, 25-34)

'I do worry about money. Yes, it probably does impact on my mental health, and on my other health issues.' (Gary, 55-64)

Section 7: Additional Costs Due to Ataxia.

Interviews and focus groups explored with participants whether they faced any additional costs.

One participant reflected generally on the amount of funding available to support them when they had been diagnosed with ataxia, what was available now, and what might be available in the future:

'The NHS was in a better situation 10 years ago. They came out and gave me lots of equipment. I got a wheelchair from them 4/5 years ago. I got appliances for the kitchen, though I don't use them anymore. I am very fortunate that I was taken care of. My treatment has been taken care of by the NHS, I get pretty much everything through the NHS, but what will happen in the future?'
(Rachel, 45-54)

Mobility Related Costs.

Participants had spent money on a variety of mobility aids including:

- Wheelchairs.
- Zimmer frames.
- Rollators.

Many participants had a mixture of mobility equipment that they had received free of charge or purchased themselves:

'I got my zimmer frame through the NHS, very few people get one like this. I have a scooter as well, I paid for it by PIP, from the back payment I got. Other than that I have not had to buy anything, I got everything through my OT'
(Frances, 45-54)

Some participants had specific complaints about the cost of mobility equipment, and the lack of support available to meet those costs although both those quote below suggested informal ways around this:

'Lots of mobility equipment is very expensive, and I don't think that it needs to be. I had an issue with the pin in my wheelchair, I rang the supplier up and they said it would be £600 to replace all the covers. I went into a bike shop and they repaired it for £45.....Councils don't seem to think what the extra costs are with ataxia.'
(Sian, 25-34)

'You can find yourself buying from the place up in Possilpark and it can be three and a half or four thousand for a wheelchair. It can cost up to £130 to pay for a wheel, tyres can cost £40-£50.....People do buy and sell without asking for the earth.'
(Nicola, 45-54)

Other participants highlighted that they had experienced difficulty making purchases of mobility aids due to not being certain what they needed:

'When I started out I knew nothing about rollators or wheelchairs. When you are spending money yourself, it would be good to get some advice about what you should get for yourself, that's a real issue.'
(George, 65-74)

'George' estimated that he had spent £3-4,000 on mobility aids, although he had been able to grant towards a wheelchair which had enabled him to return his NHS version.

Several participants identified that the wheelchairs that they had been provided with free of charge fell short of what they needed or were too heavy or cumbersome, although one participant did describe her chair as 'sparty':

'I need an electric wheelchair because I can't push my daughter because of my COPD. They gave us a transporter wheelchair which we can't use.' (Liz, 55-64)

'The wheelchair I have from the NHS. I have to use it for any distance. It's fine but a bit cumbersome, if I had the money I would look for something easier, It's hard for my wife to lift it in and out of the car. I'd like one that was lighter and easier to handle.' (James, 55-64)

Many participants reported increased use of taxis as a result of not being able to access public transport. Others reported driving more as they were not able to take smaller journeys on foot due to their ataxia.

Additional transport costs associated with trips to get treatment were also identified by participants:

'I spend more on transport and travelling, I'm under a doctor in London so I have to travel down there.' (Peter, 55-64) **ADDITIONAL QUOTE**

Costs of Aids, Adaptations and Equipment

Many participants reported that the cost of aids and adaptations in the house had been covered as a result of those being provided or carried out after OT assessments. This was not always the case, sometimes people had paid for aids and adaptations before changes, and some participants reported making some contribution to the cost of handrail installation. More significant changes had sometimes been self financed:

'We had a new room built at the back of our house. It took 8 months for us to do, I had to use some of my redundancy money for it.' (Jennifer, 55-64)

'I had to re-lay all the floors because I kept tripping. Karndean has been suitable for my wheelchair.' (Nicola, 45-54)

One participant identified a range of aids he had installed/ used to help him deal with the dual challenges of ataxia and back pain:

'I have special utensils for cooking and voice activated lights all around the flat.' (Patrick, 65-74)

Other participants mentioned a range of adaptations that they might consider buying:

'There are a lot of things that you can buy. I have heard about hubs that switch themselves off if you fall on them and worktops that you can lower the height of.' (Melanie, 45-54)

One participant reported needing special glasses, the cost of which she did not expect would be met by the state:

'The other thing is that I need special lenses in my glasses. Ataxia makes my pupils go up and down and side to side. The optician is trying to control that with my glasses. They are £600-£700, that's a lot of money.' (Mary, 55-64)

One participant reported having an expensive deal on an exercise bike for her home:

'I have an exercise bike to keep my legs moving. It's £500 for 3 months hire. It would be £3,200 to buy, it's a big piece of equipment.' (Catriona, 25-34)

Some participants whose condition had not yet progressed too far were contemplating whether they would have to make larger alterations to their home to ensure that it remained accessible.

One participant reported receiving help through a grant from Ataxia UK which had enabled her to make alterations to her home which she would not otherwise have been able to afford:

'Ataxia UK helped with a grant for the bathroom. Otherwise I wouldn't have been able to do that.' (Anne, 75 plus)

Basic Living Expenses Costs and Support Around the Home.

Participants spoke about meeting a number of additional costs associated with their ataxia, including the need for:

- Heating to be on for longer due to them being in the house all the time and not being mobile, one participant reported that this was exacerbated by the side effects of the medication he was on to assist his mobility.
- Gluten free food.
- Vitamin supplements (one participant quoting a cost of £20-£30 pounds a fortnight).
- Buying grated cheese and pre prepared veg at extra cost due to difficulties preparing food.
- New crockery to replace smashed plates and cups that were constantly being dropped.
- Ensuring that hotels and other places to stay when on holiday.

Those not yet claiming PIP were also facing prescription costs:

'I have my prescriptions to pay for. I am now looking into how to get them paid for, I have never had to look for support before, it [claiming benefits] was never a world I wanted to get into so I am treading carefully.' (Suzie, 45-54)

A significant number of participants paid for help to carry out tasks around the home. 'Peter' was fairly typical in terms of the type of support purchased:

'I pay for a lady to do a bit of shopping and she tidies the flat. I try to tidy as I go around, but she comes in and gives it a bit of a birthday. I would like to have her in more often, but I can't afford it.'

Others were topping up the money they received to pay for a personal assistant to buy additional hours from the assistant or someone else.

Additional Treatment Costs.

A number of participants were paying for physiotherapy support to help them manage aspects of their condition, for example their tendency to be slower to recover from muscle pain or discomfort. Those amounts could be quite considerable:

'I get a lot of physiotherapy. If I am lying oddly or hurt myself I used to be OK in 24 hours, now the pain can go on for weeks, I need to keep myself supple so I don't have any problems.....I am spending £1000 a week on treatment for ataxia, that's a lot of money.....I also have balance boards and go to the gym, I do yoga and pilates to keep myself going.' (Suzie, 45-54)

Others were employing personal trainers, often reporting that the trainers were people with some understanding of the specifics of their condition.

Some participants were paying themselves for other fairly standard treatments which they needed frequently:

'When you have ataxia you clench your toes when you walk which gives you foot problems such as ingrowing toenails. You have to see a podiatrist every month, you can't get that on the NHS.' (Graeme, 55-64)

Others were turning to alternative therapies, including acupuncturists, to help with balance, herbalists and Ayurvedic practitioners, and chiropractors:

'I spend money dealing with some of the pain that ataxia causes me because I walk in different ways. I have gone to see a therapeutic chiropractor for pain in my lower back, I've gone to see a chiropractor and an acupuncturist, it's an increasing cost because I am going more often. That's not covered by the NHS.' (Jimi, 45-54)

Section 8: Engagement with the Benefit System.

Survey Responses

Benefits

- There was a significant split in the extent to which respondents were receiving their income from benefits.
- The majority of respondents received either the vast majority, or in contrast very little, of their income from benefits:
 - 4 in every 10 received 20% or less of their income from benefits.
 - 3 in every 10 received at least 80% of their income from benefits.
- The most commonly claimed benefits were:
 - Personal Independence Payment/ Disability Living Allowance, claimed by 58% of respondents.
 - State Pension, claimed by 30% of respondents.
 - Employment and Support Allowance, claimed by 27% of respondents.
 - Council Tax Support claimed by 25% of respondents.
 - Housing Benefit, claimed by 17% of respondents.
- Given the age of respondents, and the level of impact on their lives of ataxia they reported, it is perhaps surprising that only 14% reported claiming Attendance Allowance. This suggests there is potentially a significant level of underclaiming here.
- The survey identified clear issues in terms of respondents' understanding of the benefits system:
 - 70% of respondents felt that their understanding of the benefits and tax credits they were entitled to was at best fair, half of those that it was poor or very poor.
 - Only 19% felt that it was good, 11% that it was very good.

Experience of Applying for Benefits

- Respondents were more likely to report poor or very poor experiences applying for benefits than good or very good experiences:
 - 47% v 24% in relation to face to face assessments
 - 45% v 29% in relation to communication with the DWP before a decision.
 - 40% v 28% in relation to communication with the DWP after a decision.
 - 37% v 30% in relation to the completion of application forms.
- Responses to a further question identified one potential cause of this lean towards negative experiences; respondents were more likely to report that the DWP system took account of their ataxia badly or very badly than well or very well in three situations:
 - 46% v 23% during a face to face assessment.
 - 39% v 25% when they were applying for benefit.
 - 39% v 30% when reaching their decision on an application.

Interviews and Focus Groups

Interviews and Focus Groups explored participants experience of all stages of the process of applying for benefits, becoming aware of entitlements; submitting applications; attending assessments; receiving decisions; and making appeals.

Participants also reflected on the use they had made of disability benefit that they received, and how well they felt the system reflected the needs and circumstances of people with ataxia.

Awareness of Entitlements / Accessing the System

Many participants mentioned that at the start of the process of applying for benefits they had not known what they were able to apply for.

Some had managed to find out entitlement information for themselves, although some misconceptions were still apparent here:

'I am getting Attendance Allowance. As soon as I was diagnosed with ataxia I read up on it. I did some research on the benefits you get with disability. I quickly realised that I couldn't get DLA because I was in work [this is incorrect]. I realised that Attendance Allowance was appropriate because I was falling at night.' (George, 65-74)

Other participants had checked their entitlement to benefits directly with the DWP, one talking about finding out she had not paid enough contributions to access either JSA or ESA.

Participants had often been told by health professionals that they were entitled to apply for benefits. In some cases they had been told by members of their family. The information they were given was not always wholly accurate.

'I put in a PIP claim in January I have no idea whether it will go through or what will happen. Someone I met said I should apply. The doctor said I should apply for Attendance Allowance but I saw that was for over 65s only [this is correct] or if you had less than 6 months to live or something [this is incorrect]. I understood that PIP was the next thing to apply for, so I did that.'

(Suzie, 45-54)

'I wasn't aware that I was eligible for DLA. It wasn't until someone told me I could get it. It was my niece because her husband is bad with arthritis. I didn't think that I would have got it, or that I would ever have known about it.'

(Anne, 75 plus)

One participant described how her awareness of her benefit entitlement had grown over the years of her engagement with the system:

'I have a good understanding of benefits now, I didn't at the start, I picked it up over the course of 20 years.' (Sian, 25-34)

Some participants had been told about possible entitlements but had not yet decided to make an application:

'I don't claim any benefits. My friend's mum said I should go along to the CAB and claim DLA. I would love a blue badge, I don't drive but it would help people with me to park nearer to things so I wouldn't have to walk so far from a disabled space....I had heard about PIP and DLA before, I just thought they were for people in wheelchairs, severe cases. If my friend's mum hadn't said to apply, I wouldn't have through I was entitled. The neurologist, physio and the doctor didn't say anything.' (Danielle, 25-34)

One participant reported that she had decided not to go for benefits that she was probably entitled to because of stories she had heard about the experiences of people who had gone through the system:

'I am probably entitled to lower rate PIP, but there is not a cat's chance in hell that I would try for that. Having to describe things every three years, I think benefits are a no-no for me because of what you go through.' (Kate, 35-44)

For some participants the issues associated with applying for benefits concerned a lack of understanding of their entitlement, and a feeling that they might not qualify, or in some way might get caught out, mingled with a sense that the process might be unpleasant:

'I don't know that I could [apply for PIP]. I'm not sure that I would qualify. I'm looking at walking aids. I have heard from other people that the assessment is so rigorous, if you can do anything, they will know.' (Jimi, 45-54)

Some participants reported feeling morally uncomfortable about applying for benefits, or had needed some encouragement to do so:

'It was difficult [going for ESA] I have always worked and my family has always worked. But my mum said that I have paid, and my sister and brother live abroad, so I should apply.' (Melanie, 45-54)

'One of the social workers told me about it. She told me I could justify doing that, she said I could do it. It took me a while to get my head around that....I don't think I would have discussed DLA without the social worker. I hadn't accepted what had happened to me.' (Rachel, 45-54)

Others saw claiming as something that they would do in the future without worrying:

'I'm not claiming any benefit yet, thank goodness. I'm not claiming Attendance Allowance, I mean it's good that I'm not entitled yet. I wouldn't have a problem doing it if I was, I would think 'why not apply' if I could get it? If the help is there, I am happy to take it.' (Ray, 65-74)

Completing applications and Engaging with the DWP

Many participants focused on the fact that they found handwriting the forms for benefit applications very difficult, some had help from family members in this task, others had left it to those family members. It was a source of annoyance for some that it wasn't possible to complete applications for disability related benefits online:

'The form I had to fill in was very long. It took me four weeks. I can't really write but I had to handwrite the form. I put down that if they wanted to know anymore they should contact me. My husband helped a lot but it was just a long winded form, I knew that I had to do it.' (Suzie, 45-54)

Some participants felt that the time they had available to them due to giving up work or reducing hours left them able to carry out some of the application process themselves.

Engaging with the DWP over the phone could be a challenge for many participants, both in terms of making themselves understood, and in terms of understanding what was being said to them:

'I did the application comfortably. It's more of a worry in terms of the phone. I worry about not hearing people, and them not understanding me. I can't just hang up because it's something that I need. When you have ataxia speech can

be a real struggle, people just hang up sometimes because they think you are drunk.' (Nicola, 45-54)

'For ESA I was on the phone a long time. It was hard to make them understand. I found that a bit annoying.' (Gary, 55-64)

Participants did suggest that forms had to be completed in particular ways if an application was to be successful:

'Filling in forms you have to get into the civil service mindset. You have to relearn a lot of things and think differently. You have to fill in forms the way they want. I thought I could sail through the assessment, I did it in my own style and I got turned down.' (Patrick, 65-74)

It was felt by some participants that application forms were designed to catch out applicants:

'I had to go back and check that I had answered things appropriately. There are designed to trip you up.' (Malik, 65-74)

Others had not struggled with form completion but felt that others in their position might:

'I don't want to sound too arrogant, I'm a general management consultant used to doing forms professionally. I don't find them difficult. I really feel for people without that experience of handling paperwork, forms can be bureaucracy gone mad, tax returns, things like that.' (George, 65-74)

One emotionally challenging aspect of applying for disability related benefits was identified by both carers and people with ataxia, the need to describe accurately the impact of the condition on their lives or the lives of people in their family:

'You try and talk about your children and you always want to say that they are good and they can do things. That's not the way you do a DLA form, that's about your worst day.' (Hamed, 45-54)

'It feels stressful when I think about PIP. I don't want to accept my disability. Part of me is still trying to get my head round my disability. Because I take each thing as it comes, I concentrate on making my meal, whatever I have to do, each thing in turn, and then you write it all down and you say Oh My God it's bad.' (Rachel, 45-54)

'Frances' had a slightly different angle on this issue, focusing on the specific consequences of a genetic condition impacting on different generations:

'A lot of adults may have children with the same condition. They can't be seen not to be able to do things. If my daughter sees that I can't do things, she'd think that she won't be able to do them. I want her to believe that she can pretty much do anything she wants to, I don't want her to believe that she can't do this and that.' (Frances, 45-54)

Other participants were less perturbed by the personal nature of information shared during applications, reflecting that they already had to regularly discuss the impact of

their disability and personal issues with other people. One felt that his personality helped him in this regard:

'I'm a brutally honest person who tells the t(Suzie, 45-54), I was OK talking about the issues that I face even though things could have been painful.'
(George, 65-74)

Others were simply nervous about any contact with the DWP:

'Dealing with the benefit authorities has left me with a fear of opening letters. When I see a white or a brown envelope I get palpitations.' (Liz, 55-64)

Participants reported that the contribution of the health professionals they worked with providing supporting information could be critical to a successful application. This could include information from neurologists, GPs, physiotherapists and occupational therapists. 'Hugh' summed up the effort that could be involved in pulling together the supporting information:

'We are able to get all the letter sorted for 'Calum', all the 'ologists' that he was under; oncologists, neurologist, everyone, and that weighed heavily.'
(Hugh, 45-54)

Some participants had experienced difficulties with the content of some of the supporting documentation that they had submitted with their application, or with getting professionals to write supporting reports:

'For my son the DLA application was straightforward. For my daughter the school plan was a problem. It said she is active at the gym. She is, but she can't do the distances that other children can. The DWP didn't seem to understand fully. I ended up doing an MR.' '(Hamed, 45-54)'

'At the start it wasn't easy because he had an undiagnosed learning disability. It was a stroke of a pen, they don't do assessments. I said 'Come out and see him for ten minutes'. You couldn't get a professional to write an up to date report if there was no change. The DLA people too see there being no change as there being no problem any more. It is very difficult to get a professional to do a report without paying.' (Rebecca, 45-54)

One participant captured her experience of a range of issues:

'When I went off sick I had to apply for SSP. I had never had to deal with the DWP before. There had been a number of horror stories about people applying for benefits that I had heard. I thought it would be five minutes to apply for, but an hour later.....I felt violated. They asked me everything about her financial situation. Having to complete the form was awful, it gave me a real insight.

That initial phone call to the DWP, they were asking for all sorts of information. When I asked them to speak slower, they did for 30 seconds and then reverted. I said I hadn't got all the information together, they said we will phone you back in 20 minutes, I said 'are you having a laugh?'

Cognitively I am fine but emotionally it was draining. Help with the practicalities would have been good. I can imagine what it would be like for others, I am quite a sturdy person and it was still hard.'

The form was intrusive and it was stressful, but it was also practically difficult to do, I can't use a computer well and I struggle to write. I had to do it in stages, it took me 4/5 days to complete. There was a level of detail that was needed and it was important to get it right because I needed the money.' (Alex, 35-44)

Some participants were more positive about the experience of applying for benefits, the positivity of the experience had been a surprise to some:

'The experience was good for me. I had heard lots of negative stories from people who have dealt with the DWP, but when it came to applying I didn't really experience many problems.' (Claire, 25-34)

'The process of applying for it [DLA] was quite easy, it wasn't a problem, when I arranged the blue badge the woman made me aware of it. The mobility allowance application was OK. I can't remember much about it, it all went through quite easily, I can't remember it at all, I don't see much problem with what happened.' (Frank, 75 plus)

There was also a degree of understanding that applying for disability benefits was inevitably going to be fairly complex:

'I know that they need to make sure that benefits are getting to the right people, so I wasn't expecting a one pager. They shouldn't give out benefits willy nilly, so I understood why they were asking all the questions.' (Suzie, 45-54)

There could also be annoyance at having to complete separate applications for ESA and PIP:

'When I was going for ESA after PIP I had to provide all the information again. I had to go to an assessment. I had to try and start from the beginning and explain from the beginning what ataxia was.' (Gary, 55-64).

Two participants offered reflections on applying for Access to Work the programme designed to help disabled people enter or stay in employment, one positive, one less so:

'Access to Work was fairly straightforward. I spoke to someone on the phone about the background. They came out and did a workplace assessment, which I thought was quite odd, because it was about my workplace environment and what I was doing there, and the issue was actually me coming to and from work, but perhaps they needed to look at that. It was a quick assessment and quick turnaround. They got in touch with my employer and it was pretty easy.' (Hari, 25-34)

'Calum' has to get taxis to work. There is a lot of palaver filling in forms for Access to Work. It's been a pain in the backside so we stopped doing it, but it's £6.50 a day, and that doesn't seem fair, so we will start that again' (Hugh, 45-54)

Attending Assessments

A number of participants reported some degree of flexibility in the organisation of their assessments, with assessors coming out to their home to carry out the assessment, or not having to be assessed at all for particular benefits. One participant reported that a work capability assessment had not been carried out after she had made it clear that her daughter could not communicate well, although she remained concerned that the issue of a further assessment would arise again.

Participants consistently reported that they had found the assessment process for PIP or ESA, or anticipation of it, to be very stressful, sometimes as part of general worries about engaging with others who might not understand their condition, or that they found anticipation of an assessment very stressful:

'I haven't been transferred to PIP yet. I am terrified of it. I dread seeing brown envelopes land in the porch, my heart skips a beat. On the helpline you do hear all the horror stories, and that can be all you read about as well. You can lose perspective.' (Alex, 35-44)

Some felt that this stress had actually had negative consequences for their condition and their health. This could be despite more positive treatment from those involved:

'I found the assessment quite stressful It was like, 'not this again.' The man himself was quite nice. In Scotland they don't have ATOS, he understood what he was talking about for the most part.' (Sian, 25-34)

'I was quite stressed at the assessment. I was quite forceful. I was asking him- have you read about it? Do you know what happens to me when I get stressed? He [the assessor] was really nice.... They gave me the benefit I needed for the longest time.' (Petra, 45-54)

Some of sources of worry referred to by participants were practical:

'I slur my speech a bit, it's frustrating and embarrassing.' (Fraser, 35-44)

Other participants had more mixed feelings about the prospect of assessments, despite stories that they had heard:

'I haven't transferred to PIP yet. Thank God for that. I have heard horror stories. I have been on DLA since I was 16, I don't really worry about PIP, my condition is fairly obvious. If you saw me you would think I was disabled.' (Catriona, 25-34)

Some participants were very negative about their experience:

'With ATOS. It was awful It was calculatedly dehumanising. I wouldn't wish such a thing on anyone, even Stalin'. (William, 55-64)

A smaller number of participants were more positive:

'I didn't find it stressful at all. I have to use a wheelchair but the building was accessible. The only problem with this was that I couldn't attend alone, so my sister had to take a day off work as well. My assessor was a mental health nurse who was very friendly and actually gave me good advice on my mental health. It was worthwhile just for that.' (Claire, 25-34)

Talking about personal issues at assessments could be difficult or embarrassing for carers or people with ataxia:

'They asked how she wipes her backside, that was embarrassing.'
(Gareth, 55-64)

Some participants felt that they had not had an assessment that reflected the reality of their situation:

'The person at the assessment took no cognisance of whether I could actually do certain things. They looked at some of what I could do and said I could drive and plan a journey. We went to a tribunal.' (Sandra, (55-64)

'The process of doing PIP was horrendous. The forms were long, I understand why, that's fair enough. I had to go to a place in Glasgow, I had to walk into this room, they said to her, you did that without stopping, but I said it was where I had to get to.They said I was well dressed, well presented and well spoken, but that had nothing to do with my application.' (Frances, 45-54)

This could involve being inappropriately asked to undertake particular physical tasks:

'They try and get you to do things which seem quite arbitrary. They asked me to look at the ceiling and to walk in a straight line, neither of which I can do, so I refused.' (Liam, 35-44)

Some participants felt frustrated that they were placed in a position of having to exaggerate or overemphasise the negative impact of their condition at assessments:

'I think you sometimes have to make things sound a little bit worse, and explain why things are not OK.' (Nicola, 45-54)

'The actual experience wasn't too bad, but I think you have to exaggerate how bad it is if you want to get the benefit, and I think that's sad.' (Melanie, 45-54)

Some participants were not impressed with the skills or knowledge of the assessors they had dealt with:

'If they were real doctors or nurses they would work in the NHS. They tell me that they are qualified in all the things we are discussing, but....'
(Gareth, 55-64)

'The person doing the assessment didn't seem to be knowledgeable. I had to explain everything to her, she was a lay person, I didn't feel she was very professional.' (Liam, 35-44)

The way that assessors engaged with them dismayed some participants:

'The DLA medical was horrendous. She was typing away and not listening to me. They don't understand what the condition is. Even when you send them the information they don't understand that.' (Graeme, 55-64)

'The first time I was at an assessment, I was treated like a liar.'
(Sandra, (55-64)

There was a sense from some participants that the assessment process was designed to catch them out:

'I was in a state when they came to my house. It was making my anxiety 10 times worse. I held it together and was just honest with her.

They would try and trip you up. They would ask you some question and then go back. They would ask you in different ways, they are very sneaky in the way they do it. They are very clever, they are very charming. They push you on certain things you have said to see if you can manage.' (James, 55-64)

'Liz' outlined the extent of what she felt was underhand behaviour in the delivery and organisation of the assessment:

'I was lied about by the nurse who did the interview. I am very glad that I had someone there to support me. I was accused of having aids fitted at my own cost and that I didn't need them. I was able to show that they were paid for by the NHS.

The length of the room is the length of the distance you need to be able to walk. They leave bottles about the place to see if you can pick them up, you are on trial.' (Liz, 55-64)

Concerns about being caught out did make the experience more stressful, one participant referred to feeling worried that they would see her walking and think that she was OK and therefore refuse her application.

Decisions and Appeals.

A number of participants felt that the decisions they had received on their claim were wrong:

'When I got PIP in Dumfries it actually went up quite a lot. They had got it wrong the time before. I think they got it wrong this time too. I got nowt on some of the questions.' (Sian, 25-34)

'Frances' who reported severe mobility issues, and had suggested that the assessment had focused on things that weren't relevant found her claim rejected:

'I got knocked back altogether. I got zero points for mobility and some points, but not enough, for care.' (Frances, 45-54)

There was a sense from participants that the rejection of applications was sometimes deliberate.

The transition from DLA to PIP had seen some people lose at least some of their entitlement. Some participants had fallen foul of other issues associated with welfare reform:

'They said I was fit to work but not fit to do anything. I wasn't entitled to JSA because I couldn't do anything that they sent me to. They said I wasn't sick and I could work.' (Sian, 25-34)

Others had just avoided being hit by aspects of welfare reform, 'Hamed' reported that he had just managed to submit a claim for child tax credits prior to the transition to Universal Credit, which had saved him from being hit by the introduction of the two child limit.

Some participants had decided not to appeal against a benefit decision for fear that they would end up losing what they had:

'I am only getting lower rate mobility. I think I should be getting higher rate, but I've not done anything about it, I worry I would lose it all.' (Liam, 35-44)

A number of participants reported that decisions on their appeal appeared to have been relatively straightforward, although the actual process could still be very stressful:

'I had to appeal for PIP, I failed by one point, I got 11 points instead of 12. They awarded it to me straight away when I appealed.' (Peter, 55-64).

'It took a year to go to tribunal. I was there with a judge, the DWP and someone else. They were nice but from the minute I was in there I was shaking like a baby. I was so stressed and embarrassed I felt as if I was begging. I was given a three year award there and then because I was so upset, they called me back and said that they didn't want me to leave without knowing.' (Liz, 55-64)

Others had more difficult experiences at the tribunal:

'They asked a lot of questions. One of those was about where I was dropped off. There was nowhere to park and they said that's 300 metres you have walked and I said that I couldn't do it without stopping. They said that was further than I said I could walk, and I said that I stopped a number of times. I found it very difficult. Maybe I would have found it easier if I was better at expressing myself, I find it quite difficult.' (Frances, 45-54)

'With [(Liz's daughter)] I had to go to a tribunal because she only got lower rate care. The judge asked me about her waterworks and I spent 15 minutes talking about that. The second person asked the same. The judge looked at them as if he didn't understand, I couldn't believe I was being asked the question again. The judge asked what she thought [(Liz's daughter)] should get, and that's what I ended up getting.' (Liz, 55-64)

Some participants reported that their appeal process had been slow, in one case that they had waited 8 months for a decision before being told three days before the tribunal due date that their appeal had been successful, something that had left them unimpressed.

Use of PIP/ DLA

Participants reported using PIP to cover the costs of activities and support that helped them live with/ manage their condition and improve their wellbeing:

'I have a gym membership, for that for the things I need for my quality of life, so that it's as good as it can be.' (Liam, 35-44)

PIP was seen as essential to people remaining mobile, in terms of being able to afford to keep their car, and avoiding inaccessible public transport:

'We would have lost our car if we didn't have PIP. Public transport is a real problem, it just hasn't been adapted properly.' (Hugh, 45-54)

'All the mobility part of PIP goes on my car. I can still drive but I never really go far, just back and forth to the workplace. The mobility covers my tax and insurance, so I don't have to pay out anything other than fuel.' (Claire, 25-34)

The fear of losing that support could make thinking about the benefit system and a potential transfer from DLA to PIP stressful:

'If they took away my entitlement to my car. We live out in the country and it's a necessity. I wouldn't be able to see my friends. If that stops, and you hear all these horror stories.' (Rachel, 45-54)

Others saw the benefit of receiving PIP in less stark terms:

'It wouldn't make that much of a difference to our lifestyle without PIP, but we wouldn't have had an up to date care that we could rely on.' (Kenneth, 55-64)

Many participants were clear about the importance of DLA/PIP as a contribution to their household budget:

'Without it, things would be very difficult. We couldn't manage without that. We can survive on benefits, without DLA it would be a very difficult situation.' (Graeme, 55-64)

Parent carers interviewed were clear that the additional income from PIP and DLA was used both specifically to meet their childrens' needs and to boost their overall household budget:

'The DLA money goes into the household budget. It goes for anything that my children need, it's not me and my wife that need things. It helps with things like paying the rent and heating. It helps with every aspect of life.' (Hamed, 45-54)

'PIP goes into the household budget for the things that we need to be getting. I take 'Jade' to the cinema with it, that's her thing, and we have a cup that she can use so she doesn't get scalded. Most of it goes on bills.' (Liz, 55-64)

'Jennifer' reported on how the PIP money received by her adult daughter 'Sophie' was managed and used:

'Her PIP is her own, but she does make a contribution and I don't think we could manage without it. A percentage of the PIP goes to the car, a percentage goes to the household. But her money is her own business. Sometimes I think she is onto a good thing. But I don't like to say anything.' (Jennifer, 55-64)

Reflections on Entitlements and the Process Overall

There was a sense from some participants that disabled people did not receive what they were entitled to from the system.

Participants often felt that the system did not take full account of ataxia, or show much understanding of people with ataxia. This could be at a fairly basic level concerning accessibility, one assessment centre being described as being on the third floor of a building, but also in the way things were conducted:

'When the person came round [to conduct an assessment] she didn't want to know anything about 'Sophie's' condition. She just wanted to know about what impact it had on her life and what she can't do.' (Jennifer, 55-64).

The system's failure to understand ataxia was not seen as unique in this regard, with participants suggesting that they consistently encountered a lack of understanding of their condition, including from GPs. Some participants suggested that even if the people they encountered understood issues around ataxia in general, those people might not understand their specific ataxia.

'One of the challenges is that ataxia it is difficult to say in that it is progressive, and people will need more and more equipment and help. There sometimes seems to be an absolute lack of understanding that they are not dealing with a static condition. There is a complex range of impacts, and people's experience is difficult. ' (Alex, 35-44)

Others suggested that although their assessors hadn't heard of ataxia, it hadn't affected the decision on their claim.

Participants had often found the process of applying for benefits very time consuming:

'I dealt with the DWP by myself. That's why it took 6 months. It's a minefield that I went through by myself. I wish I had been able to get some help. It would have sped things up.' (Sian, 25-34)

Some participants felt that the system should be made easier who had been diagnosed with identifiable progressive conditions:

'The ESA assessment it was like they didn't believe me. I think when you have a progressive condition it should be made easier. By the time he was applying for the benefit they knew I had ataxia.' (Graeme, 55-64)

The time limited nature of awards could be a source of concern, and some participants highlighted that it did not make sense in the context of the condition being progressive:

'She [the assessor] said that we should keep the paperwork because it might be reviewed at some point, but it's a progressive condition..... They said don't be surprised if it comes up again, 'Sophie' wasn't stressed about this, I was.' (Jennifer, 55-64)

'Tracey' gets worried. The first award was for three years, but they recontacted her after 18 months. We've been about 15 months at this point, we think they will come to us in November.' (Gareth, 55-64)

'The DWP changed that to a two year award. I am now in the second year, I feel like crying just thinking about it. ' (Liz, 55-64)

Associated this was the sense that there was inconsistency and uncertainty in the way that the system operated:

'I got 10 years. But then I was called for reassessment, though they didn't call it that, they called it something else. I thought I could lose it all again.'
(Sandra, 55-64)

Some participants did not understand the reason for having to have separate assessments for ESA and PIP, whilst others erroneously believed that the processes were linked in some way:

'I had to do 50 pages for ESA, and then you get called within 2 months [for PIP] to ask you all the same questions.' (Gareth, 55-64)

'I didn't have an assessment for ESA. I think that must have been the PIP assessment. They must have told the PIP people.' (Peter, 55-64)

Some participants did not see any reason for there to be any medical assessments when people had already got letters from medical professionals about their condition, and felt that this illustrated the lack of trust of applicants within the system:

'I can't really understand why there is a medical assessment. I already have letters from doctors describing the things I have. It feels like they are trying to catch you out, to make sure that you are not lying.' (Liam, 35-44)

Some participants felt that the benefit system treated their specific circumstances unfairly or inadequately:

'Everything we have looked at, we can't get. Carers Allowance, tax credits etc. If 'Sophie' lived next door we would get everything. We get penalised for keeping her at home. I think it's really unfair that I can't get paid for being 'Sophie's PA'
(Jennifer, 55-64)

Participants also reflected on where the responsibility for problems with the system lay:

'You can blame the assessor or you can blame the designer of the form. The assessor has to go point by point. The designer is different, if there is a problem, it is with the designer of the form, not the person assessing. It should be possible to design a user friendly form.' (Malik, 65-74)

Section 9: Debt and Money Management

Survey Responses

Use of Credit

- Just under half, 46%, of respondents had used some form of consumer credit in the previous 12 months, 54% had not.
- 26% used a credit card that they did not pay off every month, 20% had a bank overdraft.
- There was some use of non mainstream lending amongst respondents:
 - 8% used catalogues and 7% storecards.
 - At the higher cost end, 2% were using payday lenders, and 2% home credit, rent to own or pawnbrokers.
- These figures compare to those in the FCA's 'Financial Lives' Survey², which also showed 46% of UK adults using some form of regulated credit in the last 12 months, and 6% of UK adults using high cost credit.

Experience of Money Problems

- Respondents were asked about whether they had struggled to pay their main household bills over the previous years.
- The majority had not, 74% of respondents had not fallen behind any main household bills over the last year. However, the 26% who had fallen behind constitute a significant minority.
- 17% of all respondents had fallen behind on utilities bills, 14% with council tax/ water rates, 12% with their TV licence, and 10% with their mortgage/ rent payments.
- In relation to problems with their use of consumer credit, 14% of respondents were behind on payments on one or more consumer credit agreements, nearly 3 in 10 of those accessing consumer credit, 2% on five or payments.
- 37% of respondents felt very much in control of their level of borrowing and repayments they were making, 25% felt in control, and 29% felt reasonably in control.
- However, 5% felt not at all in control, and 4% not in control.

Impact of Ataxia on Borrowing and Repayment

- Significant minorities of respondents felt that their ataxia had an impact on their borrowing and repayment behaviour.
- 43% of respondents felt that ataxia had not had an impact on their ability to access credit, 41% that it had been at least somewhat significant.
- 41% of respondents felt that ataxia had not had an impact on their ability to repay what they had borrowed, 41% that it had been at least somewhat significant.
- Around one in 10 respondents for both the questions above felt that ataxia had had a very significant impact on both these issues.

Money Management

- There was a wide spread of views from respondents relating to their confidence at managing their money, and their knowledge about money, with a small minority experiencing real challenges:
 - 32% felt very confident and 20% felt confident.
 - 32% felt fairly confident.
 - 10% did not feel confident, and 5% felt not all confident.

² 'Understanding the Financial Lives of UK Adults' FCA 2017- used throughout this section.

- These figures compare to 37% of respondents in the FCA's 'Financial Lives' Survey having high levels of confidence in managing their money, 39% being moderately confident, and 24% having low confidence.
- There was a similar spread of views from respondents relating to their assessment of their knowledgeability about financial matters, although there was a shift in the direction of lower ratings:
 - 15% felt very knowledgeable.
 - 29% felt knowledgeable, 40% fairly knowledgeable.
 - 12% did not feel knowledgeable, 4% felt not at all knowledgeable.
- These figures compare to 16% of respondents in the FCA's 'Financial Lives' Survey reporting high levels of knowledge about money, 38% moderate knowledge, and 46% low knowledge.
- Half of the respondents have high levels of faith their money management;
 - 31% of respondents felt that overall they managed their money very well.
 - 19% felt that they managed it well.
- However:
 - 41% felt that they managed their money only satisfactorily.
 - 9% felt that they managed it badly or very badly.

Financially Aware Behaviour

- Switching between providers of basic goods is a key aspect of financial capability.
- Only 19% of respondents had not switched key household suppliers over the last three years to get a better deal (although there was significant skipping of this question, with 32% no answering it).
- 50% of those responding had switched energy supplier, 41% phone or mobile supplier, 40% an insurance provider, and 15% their bank or building society.
- FCA figures from the 'Financial Lives' Survey suggest 55% of the UK population has switched motor insurance over the last 3 years, 36% home contents insurance, and 6% their current account.
- In 2019, 24% of the UK population had switched electricity suppliers in *the last 12 months*³.

Interviews and Focus Groups

Interviews and focus groups explored participants' experiences of being in debt, borrowing money and perspectives on money management.

Debt and Borrowing Money

Extent of problems

Most of the participants had experienced no issues in terms of debt, and signalled that it was something that they actively strove to avoid.

Some participants reported getting behind bills on the grounds of not being very efficient. Sometimes they explained this by their ataxia, at other times they did not:

'I have fallen behind with bills. That's because I have forgotten. I'd get a demand and think- Oh I've forgotten that.' (Sian, 25-34)

³ <https://www.statista.com/statistics/312288/share-of-consumers-switching-electricity-suppliers-in-great-britain/>

'I think we might be behind on the electricity because we haven't sent them a reading for a while. That's partly deliberate, partly because we haven't got round to it.' (James, 55-64)

Managing self directed support personal budgets could also be an issue for some:

'I am confident about managing money, but I got into a right state with my SDS, A neighbour is helping me out, I'm lucky with that.' (Sian, 25-34)

Only one participant had reached the point of having debt recovery action taken against her, something she had found difficult:

'I have a CCJ. I missed a payment on a credit card. I didn't get help from anyone. It was frightening, I'd never been in that situation before.'
(Melanie, 45-54)

Borrowing Money

Most participants reported that they did not borrow money. This could be a long standing way of behaving, for the latter participant a way of avoiding difficulties in straightened financial circumstances:

'When we met we said to each other that we didn't want to get into trouble with money. We don't borrow money, if we can't afford it, we don't buy. We have always been that way. We have always been very good at managing money, we don't spend beyond our means, we keep a close eye on what is going out and coming in.' (Rachel, 45-54)

'If you haven't got it, you can't spend it. That works for me. We don't do debt, and we don't do credit.' (Rebecca, 45-54)

It could also mark something of a change after they had been diagnosed with ataxia.

'My husband has a credit card. I don't. I got rid when I lost my job. I felt that if I had it, I would be tempted to use it at the end of the month. I would end up down before long. I used it very little anyway' (Frances, 45-54)

'We don't borrow money anymore, we have changed the way that we manage. I definitely don't use a credit card anymore, though I used to. I still have one for emergencies.' (Graeme, 55-64)

One participant was left wondering where she could borrow money from if she needed to access it, another reported that she was still able to get credit:

'I did have a credit card when I was working. I don't now. If I did need extra money, I don't think it would be possible to get any, because I'm not working any more.' (Catriona, 25-34)

'I think the bank don't worry about me having a credit card, because I have regular money coming in like DLA.' (Alison, 45-54)

A small number of participants continued to use credit cards for a limited range of purchases and without experiencing problems, for example for Christmas or other events, whilst others had credit cards that they did not actually use. Some used their

credit card to spread repayments, others paid off card bills straight away and/or used their card to give them extra security shopping online:

'I have a credit card. I use it if things are coming up like Christmas and birthday. I might put things to do with my wheelchair on there. I've not had an issue with the amount of credit at all.' (Sian, 25-34)

'I have a credit card for internet shopping. I always pay it off at the end of each month so I don't incur interest. It's much safer using a credit card than a debit card online.' (Mary, 55-64)

There appeared to be few participants using more expensive forms of credit. One participant reported using a loan company when their child's DLA had been withdrawn at Christmas time, another that they were repaying a budgeting loan. Another participant was clear about the need to avoid high cost credit:

'I definitely wouldn't use a payday lender. My sister works for a charity which helps people like that, and she warned me off.' (Liam, 35-44)

One participant reported that she was still repaying her student loan, another had been able to avoid taking out a student loan through help from his family:

'I still have student debt. I still have that hanging over me, but I think that's the same for all students.' (Danielle, 25-34)

'I was going to borrow when I was doing my masters, mum said no, and she gave me the money.' (Liam, 35-44)

Some participants reported borrowing small amounts of money from friends:

'I might borrow five or ten pounds off friends, just small amounts like that.' (Peter, 55-64)

'I sometimes borrow from my friends. They say come out for a pint, and they will pay for my pint, or slip me a twenty for drinks. I kept some of the boys in work in the past, and they haven't forgotten that. It's awful they have to do that, they will pay everything for him.' (Gareth, 55-64)

Money Management

Effectiveness of Money Management

Participants frequently described themselves as being competent and confident about managing money, and as being knowledgeable about financial issues. Their focus on money management could extend to using a spreadsheet to keep track of their money. Taking time to manage their money effectively was often something that people reported doing, in some cases enjoying doing.

This competence and confidence was reported by participants who were under financial pressure, and in this context as necessary protection against difficulties:

'I am confident about managing my money. I just have to watch my wife [his carer] with what she spends. She just likes to make me happy. I have to keep her in check.' (James, 55-64)

Some saw their effective money management as being the result of lessons they had absorbed growing up:

'It's something my dad always said to me. Pay your bills first.' (Liam, 35-44).

Whilst some referred to having professional financial experience which helped them manage their money, others felt that their professional experience was of no benefit to them at all:

'I'm very confident managing my money. I'm accounts trained, I used to use a spreadsheet. Now I am on my own, I am in complete control of how much things cost.' (Mary, 55-64)

'I'm an accountant, but I'm useless with my own money. I only get what I can afford though.' (Martin, 45-54)

Others referred to wanting to avoid stress and worry about money, and dealing with this by being careful:

'I am good at managing money. I have to pay what I owe. It stresses me if I can't get things. I have to put enough money aside for my direct debits.' (Petra, 45-54)

Not all participants were as positive about their money management.

'Kate' drew a contrast between the financial responsibility she exercised at work, and that she did in the household:

'I make decisions involving lots of money at work. Perhaps my issue is that I don't differentiate between the two, work and home, even though they are completely different.'

'Jimi' suggested his family were not positive about his management of money:

'My wife would say I'm not competent with money. My philosophy has always been that it is there to be enjoyed'

Family Involvement

The extent to which money management was shared within couples varied:

'We sit down and work things out together, but [her husband] will be the person to make the decision.' (Kate, 35-44)

One participant referred to money management as a family effort:

'I am confident at managing money. My wife and children are good too. They know how not to spend too much. They have their schools meals at home for example. It all helps the finances.' (Hamed, 45-54)

One participant relied on his family to do aspects of his money management for him:

'My sisters pay bills for me. They help sort out the gas and electricity. They take money off me each week to get it paid. They would pay even if I didn't give them the money. I don't do that, I don't take advantage.' (Peter, 55-64)

Financial Behaviour

Some participants reported that ataxia had a direct effect on financial behaviour. This could be seen in attitudes to and control of spending, and/ or in their understanding of the importance of money, with comfort spending/ spending against boredom one challenge faced by some:

'Tracey has been using catalogues and getting into debt, and it's been difficult to deal with and stressful to get them paid. She doesn't really understand money, she just goes out and gets things.' (Gareth, 55-64)

'I think that I have overspent, I buy things online because I am stuck at home. I do some trading online too, on the foreign exchange markets. It gives me something to do, otherwise I'd sit at home. The devil makes work for idle hands.' (Patrick, 65-74)

It could also be seen in terms of forgetfulness associated with cognitive impact:

'I check my accounts every day. Before I had ataxia I was very sharp at paying bills, now it's something that I forget to do. I've forgotten to pay the water even though I have the cash card there to remind me.' (Liz, 55-64)

Ataxia was also seen as impacting on the energy and attention necessary to manage money, with a number of participants mentioning struggling with paperwork:

'I am really bad with paperwork. I used to be superefficient with documentation, now I fall so far behind because concentration is difficult. Sometimes I switch on my PC and I can't remember why.' (Patrick, 65-74)

'Kate' had a more complex take on the impact of ataxia:

'I don't know whether it's the ataxia that makes me like that around money. It's impossible to say. The ataxia is just part of me.' (Kate, 35-44)

One participant picked up on the way that benefits are paid at different times during the month as creating difficulties for money management:

'Payments come in at different times. That can make things difficult to manage. You have to make sure that you have enough left to cover. You have to be aware of things.' (Nicola, 45-54)

For others, the stability of benefits payment was of assistance in the management of their money:

'I am pretty good with bills. I don't get behind with them, I have a fixed income, I know what's coming in and out.' (Liam, 35-44)

Standard approaches to effective money management could have particular value to people affected by ataxia:

'We have a lot of stuff on direct debit. I can't always remember to pay things.' (Kate, 35-44)

'I have to have things on direct debt, I don't want to forget or not be able sort out. It would be a stress for me if I got behind.' (Petra, 45-54)

Participants reported on cutting back on particular aspects of their expenditure to save money:

'I've cut back on my Sky Package which is a luxury. I do have to think more about things like that now.' (Martin, 45-54)

Energy/ Utility/ Financial Product Switching.

The experience of switching energy providers was very common across participants, with people generally doing so using price comparison websites. Participants often felt themselves to be well informed about cheaper energy deals:

'I have changed energy supplier, they start treating you like stable customers if you stick with them and you don't get the best deals.' (Robert, 65-75)

'We keep an eye on prices on the internet, the price comparison and the money saving websites, and on the news. I think I am on the best deal at the moment.' (Mary, 55-64)

A number described themselves or their partners as being particularly keen on saving money this way:

'He's [her husband] on it like a bonnet in terms of switching. He does it every three months. He does it even though it's me that goes on Martin Lewis.' (Suzie, 45-54)

Some had found their ability and/ or willingness to switch had reduced, 'Hari' suggesting this was directly as a result of ataxia, 'Patrick' that it was weariness combined with the result of the low level of gains to be achieved:

'I used to do a lot of swapping, but because thinking takes me longer, and because I've got a full time job, I have less and less time to do the deals, I'm less motivated to do that.' (Hari, 25-34)

'I used to argue over the right price. But I felt I was winding myself up, and it wasn't making a difference. It was ten pounds at the end of a month, forget it.' (Patrick, 65-74)

Other participants suggested that they had never really seen the value in switching:

'We haven't switched suppliers for the electric. We have talked about it, but I think it's better the devil you know. I think they all claw it back in the end, even if we are paying a little more in the short term.' (Graeme, 55-64)

Some participants highlighted barriers to switching, including engaging on the phone, Other participants found the process confusing:

'I've only lived alone for a while, so I haven't switched yet. I would though. Or I'd ask a family member to do it for me, because I'm difficult to understand on the phone. I know this from the past, when I've swapped suppliers.' (Claire, 25-34)

'I've swapped providers a few times, but there are so many that you don't know which is the best.' (Gary, 55-64).

The particular type of heating system they had could also be a barrier:

'I haven't been able to switch providers. Scottish Power is the only one I can go with. I have storage heaters and no one else will take them on.'
(James, 55-64)

Some participants had experienced problems after switching:

'I have switched providers, mainly because they offered money to switch. I've now switched back, I was mis-sold. I am in the middle of an argument with them at the moment.'
(Liam, 35-44)

There was less mention of switching other utilities providers, such as mobile phone providers, and financial products, although some did talk about doing so, and insurance was sometimes bracketed alongside energy provision as a product/ service on which people were prepared to switch providers:

'We check and change our electricity provider and insurance each year, even though it takes ages. I do that side of it.'
(Rachel, 45-54)

Some participants reported being stuck with current deals on financial products such as mortgages that they were keen to switch away from due to being tied in for a given period.

'Sian' felt that switching providers to look for a better deal was not always possible for disabled people:

'I try to switch energy suppliers. But as soon as you say you are a disabled person, the price rises. I was talking about a holiday. It might have cost an able bodied person £400, but they start talking £2,000 for the same person as soon as they hear you are a disabled person.'
(Sian, 25-34)

Section 10: Financial Products and Financial Planning.

Survey Responses

Impact of Ataxia on Financial Decision Making

- A majority of respondents felt that:
 - Their ataxia had a not very significant or not at all significant impact on the short term financial decisions they take, 56% v 22% thinking it has a very significant or significant impact.
 - Their ataxia had a not very significant or not at all significant impact on their ability to take short term financial decisions, 54% v 22% thinking it has a very significant or significant impact.
- More respondents, though a plurality rather than a majority, felt that:
 - Their ataxia had a not very significant, or not at all significant, impact on their ability to take long term financial decisions, 44% v 35% thinking it has a very significant or significant impact.
 - Their ataxia had a not very significant or not at all significant impact on their ability to put money aside for the future, 43% v 40% thinking it has a very significant or significant impact.

Financial Products

- Respondents were asked about their possession of a number of basic financial products.
 - 70% of respondents had home contents insurance, a lower number than might be expected given the proportion of respondents who own their own home.
 - 37% of respondents had an occupational pension, 32% a personal pension,
 - 23% had life insurance, whilst only 7% had critical illness cover.
- Respondents were also asked about their access to life insurance, an issue highlighted as problematic in some early discussions with Ataxia UK:
 - 30% of respondents had at one time applied for life insurance and been successful.
 - 7% had applied with no success.
 - 3% had made a successful application after previously being unsuccessful.
 - 58% had never applied for life insurance.
- These figures compared to FCA findings in their 'Financial Lives' Survey which showed⁴:
 - Two thirds of the UK population with access to a private pension.
 - 28% having life insurance and 10% critical illness cover.
- Respondents were asked about savings.
- 64% of respondents had personal savings, 36% did not.
- Of those respondents with savings, some have very significant levels, 23% having savings worth more than £50,000, 28% savings worth between £10 and £50,000. However, 23% of respondents with savings have less than £1,000.
- These figures compared to FCA findings in their 'Financial Lives' Survey which showed:
 - 13% of the UK population have no savings.
 - 24% of the UK population have less than £1K in savings.
 - 19% of the UK population have between £1 and £5K.

⁴ 'Understanding the Financial Lives of UK Adults' FCA 2017- Used throughout this extion

Interviews and Focus Groups

Interviews and focus groups explored what financial products participants had, apart from loans, and the extent of financial planning they had undertaken for the future.

Financial Products.

Life Insurance

Some participants reported having life insurance or critical illness cover, sometimes through their mortgage provider, sometimes through their employer:

'Back in New Zealand I had life insurance through my employer, everyone who was working with them did. It was specifically designed not to exclude conditions, which meant it was OK with my ataxia. I was able to take it with me when I changed company.' (Robert, 65-75)

'Gary' reported no problems simply purchasing life insurance:

'I got life insurance for myself a few years ago after I had a heart attack. They had no issues about ataxia, I told them everything on the phone and they were happy.' (Gary, 55-64)

Others had been refused life insurance or had issues with accessing it, whilst some participants did not see the point of taking out life insurance:

'I haven't got life insurance, no one is going to lose out when I die.'
(Liam, 35-44)

'Alex' had won a protracted battle over access to life insurance:

'I was refused life insurance last year. I was releasing some equity from my home. I had a life insurance policy from when I was working and I wanted to increase it. My current provider came back with a very high quote, so I went to an IFA. They found a small company prepared to give a reasonable quote without underwriting.

The company asked about the ataxia and I told them. They came back with a reasonable quote subject to underwriting. They then had an issue because of the GP letter. My ataxia is very slowly progressive, everyone has a different pathway. Everyone's symptoms and rate of progression are different.

I managed to have the assessment changed, and they came back to me with a 60% higher quote. I spoke with them about the situation, they talked about it being life limiting, they said that I wasn't weren't a doctor when I challenged them. I said that she was a doctor and I co-authored the guidelines on ataxia.

They had someone who was a professor of public health with a database, that shows that even people in the medical profession don't fully understand ataxia. I have no more risk of death than anyone else. They really didn't get that.'
(Alex, 35-44)

'Jimi' spoke in some detail about his life insurance policies not paying out in response to his claim, due to the lack of inclusion of ataxia in the conditions covered:

'My critical illness cover said that ataxia is not covered by the policy. They just said that it's not included. I haven't taken advice on it. I have thought about contacting the regulator, but that wouldn't be easy when you are managing a full time job and kids. It feels beyond me.

I have 2 life insurances and 2 critical illness covers. I have one that I took out years ago in case something happened, and one that came with his mortgage. When I was diagnosed I called them and they said it was not covered by the policy. I don't think that it was excluded, it just wasn't explicitly covered. The policy is focused on what it is included, not what is excluded.....

My critical illness policy would nuke them [financial problems], it's frustrating that for a life changing illness it doesn't apply.' (Jimi, 45-54)

Some had not considered the possibility of life insurance due to the expense involved, others had taken the decision to avoid because of their feelings about the industry:

'I think pensions and insurance are legalised robbery. Insurance companies feed off people's fears.' (William, 55-64)

Savings

Some participants had some level of savings. These were used for a variety of different purposes. Smaller levels of savings were often used as a way of putting aside money for particular costs or to cover for unexpected costs:

'I have some small savings. I use them to give my children a good time, like going on a holiday. We spend on things like that. You don't know what will happen in life so we keep £2-£3,000 for critical things, to make sure we have something. That is the way that both my wife and I think.' (Hamed, 45-54)

'I have savings, but they are for now, I use them to go and see my family in England.' (Graeme, 55-64)

One participant, who had no plans to take out a pension, was saving a significant amount of money which she felt would probably be of use in the longer term:

'I have about £20,000 of savings. I'm not sure what I'm actually saving the money for. It's probably for when I have to stop working and don't have any money coming in.' (Claire, 25-34)

Others felt that their savings were not much protection in this regard and expected to be more reliant on other financial products:

'I have savings a well. They can help out in the very short term if I stop work.' (Suzie, 45-54)

Participants had often begun to spend the savings that they had to maintain their standard of living:

'I spent some of my savings trying to keep things normal.' (Gareth, 55-64)

In some cases people's decisions had also been driven by their fear of the impact of holding savings on their benefit entitlement:

'I had a little bit of savings, but not much. I had about 10K, but they [the DWP] cap it at £6K so I spent it.' (Sian, 25-34)

Other participants had not shared with the DWP that they had savings or additional payments coming into the house when applying for benefit:

'I didn't tell people about the savings I had, I wouldn't have got support. It seems unfair having to do that when you have worked all your life.'
(Gareth, 55-64)

'You can't save, it gets taken off your benefits. I've not done much saving, I was diagnosed when I was a student. My ex husband was better paid, he has a much better pension. I can't get half of what he has right now, I would get benefit taken away, so I spend the money quickly.' (Nicola, 45-54)

Pensions

Some participants had pensions. Some of those who had had occupational pensions, others had decided to provide for themselves:

'I have a couple of pensions that I was enrolled in, just things I was automatically enrolled in through work, it wasn't out of choice. I haven't got life insurance and haven't really got any savings.' (Danielle, 25-34)

'They asked at work whether I wanted a pension with them, or to do my own thing. I decided to go with my own pot so I don't have to wait until I am 67. I have built up a nice pot of money which will last me a couple of years. I'm now paying into a pension at work because the Government says that you have to, and I'm still paying into the other pot.' (Kate, 35-44)

Participants could find it a struggle to pay into a pension. 'Liam' who had managed to put away some money in an account reflected on this:

'I've got an ISA account to help with the last car payment. I've left that now it's full. If I become a writer I might use the money I earned for my pension. I think I would put some of that money away, but you do still have to pay for things.'
(Liam, 35-44)

Some participants felt that their public sector pensions were what made life liveable or stood between them and real financial hardship:

I am very lucky from a financial point of view that I have an occupational pension. It's very liveable on for a single person. I was awarded the top level of pension, that came with a £50K lump sum which made a big difference.'
(Alex, 35-44)

'Our situation is OK because of my police pension and 'Sandra's' NHS pension. Without those we would have been in dire straits, the money just wouldn't have been enough.' (Kenneth, 55-64)

One participant referred to the impact of having cashed in their pension to get out of financial difficulties, not in this case driven by her ataxia:

'They keep moving the pension age so I can't claim that for a couple of years. We had a very good private pension, but we had to cash it in for a couple of debts, I will only be able to get my state pension now.' (Mary, 55-64)

Other participants had made a conscious decision not to access their pension at this point, despite having had to give up work to provide a bit of long term financial security:

'I have a works pension, I've not touched it yet. I will just leave it, or it will be there for my wife, whichever comes first. That's why I did it, it's something for my wife to fall back on if something happens to me. It's basically my life insurance.' (James, 55-64)

'George' had developed a similar plan:

'I have a plan for my wife's financial situation. She gets 50% of my pension. She will be just about fine.' (George, 65-74)

One participant felt that the pension that he had was too restrictive, and might turn out not to be of relevance to him, as well as impacting on his benefit entitlement:

'I increased my payments [before losing his job]. I can't touch them until I am 55. I feel they are useless. I feel I'm being punished for putting that money aside.' (Martin, 45-54)

Participants also had concerns about the interaction of their pension with the benefit system, or had experienced the negative aspects of this:

'I worry about money. I have a works pension and I worry that will impact on my benefit.' (Petra, 45-54)

'I had a full pension pot with the NHS, I was annoyed to get my ESA docked [because of it]' (Sandra, (55-64)

Some participants were concerned about their lack of a pension in the future. One participant reflected that she would not be receiving the full state pension as she had not paid full contributions because of disruption to her income resulting from her no longer working, another about her lack of private pension:

'I don't have a pension that I am contributing to. That's pretty concerning. My husband is 11 years older, I know that he's likely to die earlier and I haven't paid in for a number of years. I feel that there is nothing I can do. I did try phoning people, but they said they couldn't help.' (Frances, 45-54)

Financial Planning.

Most participants reported that they had not planned far ahead for the impact of ataxia. This was particularly the case for those diagnosed later in life:

'I didn't plan ahead. I was not really sure what planning I could have done, in one sense there was nothing I could plan for.' (Robert, 65-75)

There was a sense from some older participants that much of their financial planning had been done way before diagnosis, and had not therefore been impacted by a condition that they had not realised would affect them/ they did realise they had:

'My wife and I put money aside. We have to be careful, but we have always been careful, you need to think about how long you have to live when you are making decisions about spending.' (Ray, 65-74)

'The plan wasn't affected by ataxia, I had it in place as I approached retirement age. I had been thinking about my income in retirement for a long time, now I have to think about my wife. I had already planned ahead, I'm aware that lots of people don't, and I feel sorry for them.' (George, 65-74)

The slow progress of the condition also impacted on some older participants' thinking about their finances:

'The onset of the condition has been so slow, I know it can be quicker, but it's been so slow that I hadn't really planned anything until recently, when I realised that I can't really get about any more.' (Frank, 75 plus)

Some participants felt that people with ataxia faced the same set of challenges as any others when planning finances:

'I don't think ataxia affects my thinking about the future any more than if I didn't have it. The future is a worry for everyone, thinking about care and things. I don't think it's any worse for me thinking about getting old, it sneaks up on you really fast.' (Mary, 55-64)

For some, not planning ahead was not so much about ataxia, as about just not focusing on the future in general or specific financial issues:

'To be completely honest I never gave any thought to finances at all. No one talked to me about money either. I was just like any normal person thinking about holding down a job to get a mortgage. Until then retirement hadn't really been on my radar. Things felt OK, all my money was my own, I had no dependents. I wasn't as careful as I am now, nor as I could have been.' (Alex, 35-44)

'I don't really have financial plans, you don't know what's going to happen from one year to the next. Maybe I'll get to the age of 50 and start saving for later years. I'm not really thinking that far ahead. That's a little bit about ataxia and a little bit about what I would do anyway.' (Danielle, 25-34)

'Danielle's' thoughts about her savings captured a high degree of negativity about her condition:

'If I can be completely honest, when it gets to the point of complete loss of mobility, I will start saving up to go to Dignitas. When it comes to that point I will get a plane ticket to Switzerland, I should start saving now, it costs thousands.'

One participant felt that she did not want ataxia to affect her decision making:

'Ataxia hasn't changed by long and short term decisions about money, and I won't let it.' (Suzie, 45-54)

Some participants had complex feelings about future financial planning and its utility:

'I don't think it's had an impact on planning for the short term. I tend to take just one day at a time....Ataxia does have a long term effect. I can't plan for the long term when I feel I don't have a future. I am wary about what I spend my money on, and talk myself out of making many small purchases with any disposable income that I have at the end of each month. I don't know when I will be out of employment and have to start spending my savings.'

(Claire, 25-34)

Two participants reflected that paying off of their mortgage earlier than planned had made things easier for them, even though in neither case had that been as a result of ataxia:

'We have paid our mortgage off. That was about the uncertainty of his ['Rachel's' husband's] work. He always said he wanted a roof over our head. I am grateful for that now.' (Rachel, 45-54)

'We paid our mortgage off ten years ago, thank goodness. We worked our socks off for it. We don't have that burden.' (Suzie, 45-54)

Some of the older participants were thinking about the costs involved in adapting their home to their disability, but were aware of the uncertainties involved:

'I think there will be extra costs with the adaptations and probably when I get wheelchair. I have looked at what I might need, but I haven't gone as far as to get quotes, I've got a good sense myself of the pricing. I haven't put pen to paper yet on it, I would love to be able to foresee what's ahead but I can't.'

(Ray, 65-74)

Section 11: Experience of Support with Money Issues.

Survey Responses

Support with Applying for Benefits

- Respondents were asked whether they had received support to claim benefits, and if they had, what their experience of such support had been like.
- 68% had received no support when applying for benefits.
- 15% had received support from a CAB, 11% from another independent advice organisation, 10% from a local authority advice service, 2% from a service provided by another organisation (not including Ataxia UK)
- Existing advice agencies appear not always to be meeting the needs of all those who approach them for advice. Whilst the experience of accessing advice and support on benefit issues was generally positive, the proportion of positive respondents was lower than the levels that advice agencies would expect and aim for:
 - 40% describing it as very good, and 32% as good.
 - 17% found the service that they had received merely fair, 6% had found it to be poor, 5% to be very poor.
- Part of the explanation for lower than ideal levels of satisfaction might lie in that:
 - Only 29% of respondents felt that the service they had accessed did very well in taking account of their ataxia, 26% that it did well.
 - 32% felt that the service they had accessed had taken account of their ataxia satisfactorily, but 12% felt that it had taken account of their ataxia badly or very badly.
- There is evidence that many respondents had a need for advice that was not being met at all. Of those who had not accessed support when applying for benefits:
 - 48% felt that it would have made a difference, with half of those feeling it would have made at least a significant difference.
 - 9% felt that it would have made a little difference to them, 14% that it would not have made a difference.
 - 30% were not sure what difference it would have made.

Support to Deal with Debt Issues

- Only a small minority had accessed support to deal with debt issue, 13%, with 87% not accessing support to deal with a debt or money problem.
- However, one third of respondents did acknowledge that they had experienced debt or money issues at some point.
- 7% had accessed a CAB to deal with a debt issue, with all other sources of help being used by less than 2% of respondents.
- Again there is evidence that advice agencies are not meeting the needs of all those who approach them for advice with the proportion of positive respondents again lower than the levels that advice agencies would expect and aim for those who had received such support; 35% felt it was merely fair, 32% that it was good, and 15% that it was very good. However, 6% felt that it had been poor, and 12% that it had been very poor.
- Again, the survey provided evidence for one of the potential explanations of this lack of positivity. Whilst 35% of respondents accessing debt support felt that it had taken account of their ataxia satisfactorily, 21% well, and 18% very well, 15% felt that it had done so badly, and 12% that it had done so very badly.

- Again there is evidence that many respondents had a need for advice that was not being met at all. Of those who had experienced a money or debt issue but had not accessed support:
 - 19% felt that it would have made a difference, a further 13% that it would have made a significant difference.
 - 13% felt that it would have made a little difference, 7% that it would have made no difference.
 - However, 48% were not sure if support would have made a difference.

Interviews and Focus Groups

Interviews and focus groups explored participants experience of support with money issues.

Advice Organisations

A number of participants had experience of accessing advice and support on financial issues from mainstream advice organisations.

Access

Some didn't feel that they would know where to turn for support, others were not aware that advice agencies could help them in their situation:

'I haven't thought of going to the CAB. I didn't think they dealt with that sort of thing [a problem with life insurance.]' (Jimi, 45-54)

Participants had found their way to advice agencies after referral from professionals supporting them:

'I was talking to the manager there [at the local council's social work department] She said that though she couldn't say officially because she works for the council, she recommended that I talk to Shelter. She was saying that they will have lawyers who will argue that if the children can't use the toilet properly, they will be legally homeless because there is no appropriate accessibility at all.' (Hamed, 45-54)

'It was a housing officer who said to me, you need to apply for benefits, and I will get you an appointment with the welfare rights officer. That set it in motion. The welfare rights officer was very good, she was interested in the person and in making sure that you got the benefits that you were entitled to.' (James, 55-64)

Quality of Experiences

Responses highlighted a spread of positive, mixed and negative experiences of mainstream advice organisations. Some also felt that experiences could vary significantly between agencies, even when they were part of the same network:

'The CAB were helpful, though that's not the case for everyone. It depends on which offices you go to, some are good and some are not.' (Liam, 35-44)

Some participants reported that advice services had been willing to reach out to them, others that they had been treated with real respect by those delivering advice:

'We got help from the resource centre. The woman was good, she was blunt and she said she wanted to talk to 'Calum' and not me. She said they talk to the people not the carer.' (Hugh, 45-54)

Others reported positive experiences in more general terms:

'Filling in forms was an absolute nightmare. I went to the CAB to get help. It was wonderful, it took a lot of stress off me.' (Claire, 25-34) Some participants reported that some of the basic practical experiences of accessing advice were negative:

'The CAB wasn't very accessible in general. They would hold appointments in places that weren't accessible in buildings with steps.' (Sian, 25-34)

One participant felt that the service she had received from the CAB had been less than professional:

'I got help with my initial application from the CAB. They are a lot of good people. I don't want to criticise them because a lot of them are volunteers and they must have a lot to do, but one of them did a form and then when I went back for the appeal the CAB couldn't find the same form. I'm not blaming them, it's a very difficult job and they don't get paid, but I do feel they shouldn't have lost that.' (Frances, 45-54)

'Liz' struggled to develop a relationship with the adviser she was working with, who she felt she could not make understand the complexity of her situation:

'I feel pretty intimidated by my adviser. They don't understand that some of the money is going through my account for my husband [who doesn't live with her]. I'm his financial appointee, it's money I can't use for myself. The adviser said I am spending too much money on my child [who has ataxia], and she's asked why I am complaining about paying the water rates, but I don't want to avoid payment. It's a nightmare at the moment.' (Liz, 45-54)

Another participant felt that the advice agency he had used had not pushed as hard as he would have wanted on his behalf:

'They advised me not to reapply. They gave me the sense that they were really against doing it. I felt a bit discouraged by them, like I had to not rock the boat.' (Liam, 35-44)

Some participants had had mixed experiences in terms of the knowledge of the advice agency that they had engaged with:

'I think they [local CAB] lack experience, they were not so good with DLA for children. They are experienced with PIP but they haven't got the experience with children.' (Hamed, 45-54)

Again others were more positive:

'I got help from the Centre for Independent Living. They highlighted questions in a way that I hadn't thought of. They made me think about hazards in the house, things like showering properly.' (Martin, 45-54)

Doubts were expressed by a number of participants about whether the advice agency supporting them truly understood the issues around ataxia, both in terms of the sort of support that they might need to apply for benefits, and in terms of the content of any application:

'I don't really think they understood the issues around ataxia, any aspect of it really, they don't understand the impact that it has.' (Sian, 25-34)

'I don't think they really understand about ataxia. I used to volunteer with them. I went in to see them and the staff were shocked at my condition. I didn't feel that things were that bad, I think they should have known that I would be as I was. The first time I went to see them I wanted them to transcribe something from the computer for me. I felt that they didn't understand why I would need things written down for me.' (Liam, 35-44)

Sometimes what participants saw as advisers' more limited knowledge of the condition had an impact on the outcome of benefit claims, some times it did not:

'The first person hadn't heard of ataxia before, I thought that was fair as it is rare. They didn't quite grasp what was involved. The second person I saw at the appeal stage hadn't heard of it before either, but she could see the problems and ask the questions, like 'how do you lift things out of the oven',' (Frances, 45-54)

Like 'Frances', 'Liz' acknowledged the difficulties involved in this due to the rarity of the condition:

'The CAB people don't really understand ataxia. Only people who have been affected by it or have encountered it know what it is.' (Liz, 55-64)

For one participant, issues with the advice they had received had had a significant impact on their situation:

'I got help filling out the form from a mental health project. I wanted them [the assessor] to come to my home and do the assessment. But my friends found mistakes on the form which made it look as if she didn't need to come out. It said I could go out and that made me even more stressed.' (Petra, 45-54)

Others were more positive about the understanding that had been shown:

'The resource centre 'got' 'Calum's' disability. The service we got was phenomenal.' (Hugh, 45-54)

One participant felt that the advice provider he had engaged with had understood the specific challenges of ataxia:

'The CAB were very helpful. They got what it was straight away. They had already seen someone with ataxia. That was a complete coincidence. They explained what I would be entitled to and what I should get.' (Graeme, 55-64)

Support from Others

Participants had also received help with benefit applications from health professionals which they felt had been critical to them accessing the benefits that they were due, and even in making an application at all:

'I was going to the Royal Free Neurological Hospital. I was seeing an OT who was providing me with help with the form. We did a little bit each week. I would then type up the answers back home, then we added a decent letter, not one from a physio saying 'he claims he can only do this' but one with different wording.' (Patrick, 65-74).

'My social worker helped me fill out the form. It wasn't too bad doing it, but I felt bad about it. I don't think I would have claimed DLA without her, I hadn't accepted what had happened to me.' (Rachel, 45-54)

Some participants had got support from neighbours, friends and family to deal with benefit applications or other problems, including difficulties with SDS payments:

'My brother is very good with money, he helped with the DLA form. Otherwise I don't think I would have got anything. I would just have said that I have ataxia and not mentioned any of the symptoms.' (Anne, 75 plus)

Use of Independent Financial Advisers

A handful of participants had used independent financial advisers. Experiences were generally positive, although that positivity was somewhat qualified:

'I had a financial adviser to sort things out after my mum died and we were left some money. We have a good relationship with the IFA, she has been helpful. But we are now having to pay extra because she is not making enough money.' (Kenneth, 55-64)

'They don't know about ataxia and its particular impact. Even though they say they are independent, it can be hard to get an answer.' (Martin, 45-54)

'I have an IFA. I speak to them about managing my money. That person doesn't really get ataxia. It would be much better if they did.' (Ray, 65-74)

Section 12: Current Sources of Information/ Engagement with Ataxia UK

Survey Responses

Information about Finances

- The most popular source of information about financial issues for respondents was their bank, 55% of people indicated that it was an important source of financial planning/ financial information, 13% said the same of other companies providing them with financial services.
- 19% of respondents indicated that IFAs were an important source of information about financial issues.
- 13% of respondents indicated that Ataxia UK was an important source of information about financial issues, with 8% reporting the same of other voluntary organisations.
- 13% of respondents indicated that the printed media was an important source of information about financial issues, 9% the broadcast media.
- Only 6% suggested that independent finance focused websites were an important source of financial information, 5% that the Money Advice Service was. The former figure is lower than might be expected in the context of the consistent referencing in interviews of use of Money Saving Expert.
- 18% said that none of the listed options were important sources of information about financial issues.
- Views were mixed on how well information for people with ataxia was provided from these sources, but it is clear that many respondents perceive gaps in the information available;
 - Only 29% that felt that information was provided was provided well or very well.
 - 39% felt that information was provided satisfactorily.
 - A significant minority, 32%, felt that it was provided badly or very badly.

Support from Ataxia UK with Financial Issues

- Only 7% of respondents had received support from Ataxia UK to apply for a benefit or tax credits.
- Only 1 respondent indicated that they had received support from Ataxia UK with a debt/ money issue, although, inconsistently, 11 gave an indication of the quality of the service they had received.
- 14 out of 20 who had received benefits or tax credits advice thought it was good or very good, but 4 out of 20 thought it was poor or very poor.
- 5 out of 11 expressing a view about debt or money advice provided by Ataxia UK felt that it was good or very good, 3 thought it was poor or very poor.
- The reasons behind the low though notable levels of dissatisfaction with Ataxia UK provision found in the survey are not clear. In particular it is not clear whether it was felt that provision lacked quality, was inappropriate, or if problems had arisen because the organisation did not have the capacity to provide the extent of support sought by respondents.

Provision of Information

- There were mixed views, tending positive, about the quality of the information on money and benefit issues that Ataxia UK provides on its website and in its newsletter;
 - 57% thought that the information was good or very good.
 - However, 31% stated that it was only fair, with 12% describing it as poor or very poor.

- 24% of respondents reported that they did not know what the quality of this information was.
- A minority, 15%, reported that they did not use the website or the newsletter.

Priority for the Future

- There is a high level of support for Ataxia UK to respond to the need for benefit or debt advice amongst its friends.
- A significant majority of respondents, 72%, felt that the development of provision of advice on benefits and money issues should be a priority for Ataxia UK in the context of the range of the other areas of work that it might want to develop.
- Whilst only 8% felt it should be the organisation's top priority, 27% felt it should be one of the organisation's top priorities, and 37% that it should be something of a priority.
- 16% felt that it should be something that Ataxia UK should consider, but should not be one of its top priorities, only 1% felt that provision in this area was not needed.
- 10% did not know how much of a priority this area of work should be.

Interviews and Focus Groups

Interviews and focus groups explored the sources of financial information that participants used, and their engagement with Ataxia UK and other disability organisations.

Sourcing Financial Information

Many participants made significant use of online financial information and price comparison sites. Others used print media sources such as the money section of the Daily Telegraph. Money Saving Expert was mentioned by several participants as their favoured source of information:

'The information I get is mostly from Money Saving Expert. Martin Lewis is my go to bible.' (Rachel, 45-54)

It was acknowledged that although these sites were useful, they did not contain information directly relevant to ataxia. Some participants also suggested that information could be difficult to find. Significantly, many of the older participants were keen users of the internet for access to information about money, and it was something that they enjoyed doing, although some worried that others would not be as well placed:

'It's OK for me to spend days Googling and researching. I enjoy the process. Lots of people don't know where to turn.' (George, 65-74)

Some participants relied primarily on informal sources of information on money issues, including neighbours and friends:

'I don't really have a good source of information. I go to my neighbour for advice, she is really friendly.' (Sian, 25-34)

Engagement with Ataxia UK

People had sometimes found their way to Ataxia UK simply by an internet search, others had done so only by happenstance:

'I didn't register about Ataxia UK, but my friend's mum with MS told me about them. She knows all the networks.' (Danielle, 25-34)

'I started getting the magazine when my daughter went to work for Ataxia UK, I hadn't heard of them before then. It was by accident I got plugged in, I didn't know the organisation existed. Before that I got very little information in terms of the progress of the condition and what it will be like. From the neurologist and the doctor, I got absolutely nothing.' (Frank, 75 plus)

First engagement with Ataxia UK could bring its own challenges. 'Jennifer' spoke about her shock when she first accessed information from the forerunner of Ataxia UK, although she was very grateful for the support she had received:

'I remember getting the leaflet with a picture of a little girl in a wheelchair and being told 'they will help you'. That was when it was FAC, it was only one person at the time. If it hadn't been for that woman, I don't know where I would be.' (Jennifer, 55-64)

'Suzie' felt that she was not able to cope with the information on the Ataxia UK website because she had not yet come to terms with her condition:

'I had a look at the Ataxia UK website, then I switched off before I got too far. I don't know how long it will take, but I know it is going to get worse. I am not in denial about it, I just don't want to be thinking about it all the time either. The website has pictures of people in wheelchairs on it and I thought I don't want to go there. I know I might have to, but I don't want to look.' (Suzie, 45-54)

The actual information and support provided by Ataxia UK including through their website was generally viewed positively by participants.

'I found the magazine helpful. It's got useful information from the medical profession.' (Frank, 75 plus)

'Rachel' felt that the Ataxia UK website did not cover issues facing people with her type of ataxia as effectively:

'I do think there could be more from Ataxia UK. There is lots there for people with Friedrich's ataxia, and there is lot there about ataxia in general, but not much about my condition.' (Rachel, 45-54)

'Kate' had found the Ataxia UK website a critical resource for accessing information about ataxia which she could then share with the people working with her, and with her employer:

'I use it to get information for people so they can understand. That includes GPs, I've only ever come across one who knew what it was, only one that I didn't have to explain it to. I used it with my employer and my friends. I had a bit of difficulty relating to my employer how it impacted on me. I can look fine and I can hold down a job, but it still impacts on me.' (Kate, 45-54)

Another participant had had a more negative experience of sharing information:

'We took a DVD about ataxia into [her child's] school. It was there in the classroom untouched at the end of the year.' (Joan, 65-74)'

Participants were often not aware of the range of information about financial issues, in particular benefits, that was available through Ataxia UK, even when they were aware of other support and information provided by the organisation. None of the participants reported accessing the financial information available on the Ataxia UK website, though some felt that it might be useful for them when it was mentioned by the researcher:

'I've not gone on the Ataxia UK website, it's not one of those things that comes up. I thought that their main objectives were around research and trying to find solutions, medical solutions for ataxia, not doing this sort of help. I've been along to Ataxia UK conferences to see about things. My children's conditions are really rare, you only see 3-4 published works on them, when you search it is always the same papers.' (Hamed, 45-54)

'I haven't used Ataxia UK for information about money. I suppose they do provide it. I might take a look, I'm thinking about appealing on PIP.' (Liam, 35-44)

'Suzie' felt there was a general lack of specialist support for people with ataxia:

'I don't feel that I have any support with the ataxia. When you get cancer you are given a cancer nurse to call. A lot of people don't call, but knowing someone is there is enough.' (Suzie, 45-54)

Some participants talked about their involvement in local Ataxia UK groups:

'I go along to the local groups though I haven't been for a while because other things have been happening.' (James, 55-64)

One of the participants who was heavily involved in her local group as an office holder spoke about trying to get a new initiative off the ground:

'I only know people with ataxia in their 50s, and I want to know younger people. I'm trying to get a WhatsApp group together for younger people so that we can talk to each other.' (Catriona, 25-34)

Other Sources of Information

A number of people referred to using a range of other disability focused sites in relation to benefit issues:

'I go on Benefits Adviser, and on some of the disability related sites. They are good for telling you things.' (Liz, 55-64)

The CAB website is very useful. The emphasis that it places on telling people to be clear about how their condition affects them.' (Alex, 35-44)

The information that people accessed about benefits could be quite polemical and discourage people from making an application:

'I have seen something on Youtube which talks about someone with thalidomide being asked at an assessment if his arms would grow back. I thought I wouldn't have a cat's chance in hell.' (Melanie, 45-54)

Participants reported using a range of other sources of online information relevant to ataxia including Virtual Ataxia and Ataxia Hub.

Although Ataxia Hub involved people from around the world, 'Suzie' still felt it was very useful:

'I am glad I found the Ataxia Hub. There are a lot of people from the US, but you can get support and support each other at the same time.'

Some had not used online forums at all, leaving them unconnected with others:

'I haven't gone on to online forums at all. I don't know anyone with ataxia.'
(Frank, 75 plus)

Section 13: Future Engagement in Financial Inclusion by Ataxia UK

Interviews and focus groups explored participants' views on whether or not providing information and services focused on money issues should be a priority for Ataxia UK going forward and money issues on which the organisation might campaign, and suggestions for how it might shape any money focused work and develop its other services.

Potential Areas of Work

The majority of participants wanted to see Ataxia UK take more of a role in relation to money issues, building on their expertise on the condition.

It was suggested that Ataxia UK consider providing:

- Advice on disability benefits.
- Benefit checks.
- A phonenumber which people could use to access advice about benefits and other issues.
- Information about the larger costs that people face, perhaps guiding the development of ataxia budget calculators.
- Information about benefits in the initial booklet sent to new 'friends'.
- More information about benefits in the magazine and newsletter.
- Presentations at conferences about what benefits they are entitled to and the organisations that are there to help.
- Advice for people who are struggling with household bills or other repayment of borrowing.
- A limited amount of direct financial support to people.
- Information about insurance providers.
- Information about which vehicles could be provided under the motability scheme.
- Information about where people could access reasonably priced equipment, aids and adaptations.

Some felt that Ataxia UK could emulate other disability/ parenting organisations who helped them with benefit applications or by providing information:

'They could provide information about how to apply for PIP and what to put on the form and how to apply for housing. All those sort of things. It would be really helpful if someone at Ataxia UK did what Parent to Parent do. Volunteers could look at PIP and DLA, they could help gather more information. They could give advice so you have a better chance.' (Hamed, 45-54)

'There is a role for Ataxia UK to do what My Aware do, who work with people with Myasthenia. They have advisers on the telephone who will talk to you about the financial implications of the situation.' (George, 65-74)

The potential importance of providing advice about charitable grants was stressed:

'The DLA people don't explain the grants and funding you can access. The £3,200 I pay for my bike is a lot of money. Ataxia UK should help you think about how to pay for things like this, and where to get grants from.' (Catriona, 25-34)

Participants felt that Ataxia UK should explore work around energy advice:

'I think they could talk about better deals on mobility equipment and holidays, gas and electricity. I'd like to see if there is way of getting my extra electricity reduced, to see if I can claim it back.' (Sian, 25-34)

Some highlighted potential roles for Ataxia UK around helping people on employment issues:

'I would like to know about employers and what they have to do. I never put that I have ataxia on applications forms, and I would like help to think through what is right.' (Danielle, 25-34)

'Danielle' also felt that advice on starting a business might be helpful:

'I got my advice on business from the Start and Grow Programme, which is help for entrepreneurs. It was completely free, I did a course recently at the University of Gloucestershire. It wasn't just for disabled people, and I didn't tell them I was disabled. Something on this might be helpful too.'

It was also suggested that advice around power of attorney would be helpful:

Financial power of attorney is another important issue. It's not just about the end of life. Often people drop contact with Ataxia UK as their condition progresses. People often don't have the opportunity to plan ahead for how they will handle things as their condition progresses.

It's not capacity, so much as not being able to speak, write, or use a computer, and needing someone who can assist you to communicate. Thinking about that earlier rather than later is an important thing.' (Alex, 35-44)

'Alex' questioned the value of financial advice:

'In terms of the helpfulness of financial planning, yes, it would be helpful, but there is the question of whether or not it would be listened to. I wouldn't have gone near it, so in that sense would it have been that helpful? I might have had advice but not done anything, so what would have been the outcome of that?'

Service Preferences/ Aspirations

Participants were clear about their preferences and hopes for such a service, that it would be:

- Delivered by people with real knowledge of ataxia as a condition.
- Take account of the communication difficulties that people with ataxia can have.

It was suggested that even basic information provision about entitlements would make a difference:

'If people know about something, they can get help with it, but it's as if you have to know the answer before you know what question to ask. I think it would be helpful if Ataxia UK did some work on this.' (Rachel, 45-54)

The need for some form of face to face advocacy or support was emphasised by one participant:

'It would be a really good thing to have advisers who can go places with you. It's embarrassing going anywhere. A lot of things get lost in translation when you go into places. You can't speak up. It makes it difficult to deal with the benefit or pension people' (Anne, 75 plus).

The modesty of some people's aspirations for such a service was apparent:

'It would be good to get advice from Ataxia UK, but I wouldn't want to put them out. It would be helpful to have someone in, I am a quiet person, I wouldn't go too much, but I think it would be helpful.' John

Mutual assistance was seen as something that could support people with financial and other issues:

'They should mobilise local support groups where people can meet and exchange support with others.' (George, 65-74)

Participants did acknowledge the potential limitations on what Ataxia UK could do, and had suggestions for dealing with that. Some of this work might focus on linking people with ataxia to appropriate services:

'They could refer you to the right people. They don't have to do it all, but they could connect you to the right people.' (Hamed, 45-54)

'I think there should be a list of trusted IFAs that you could go to.' (Sandra, (55-64).

'I would like to know where to go for mortgage advice.' (Melanie, 45-54)

Some of the work might also involve building up the capacity of others providing advice:

'There could be a partnership between the CAB and Ataxia UK. Ataxia could provide the information, the CAB would know the keywords.' (Nicola, 45-54)

It was suggested that Ataxia UK should also seek to ensure that professionals who are working with people making benefit claims are better informed about ataxia:

'There is lack of appreciation of ataxia. Like I was saying about physios using language about claiming to be affected, and the negative impact of that. There is value in communications with professionals, GPs and others to make sure they are talking about ataxia appropriately. It's important when they get a request, they know what they are responding to.' (Patrick, 65-74)

Willingness to Use an Ataxia UK Advice Service

Participants who had used other advice services often indicated that they would still use an Ataxia UK specialist service:

'It would be good for Ataxia UK to do stuff on this. It would be absolutely great. I would go to that, though the [welfare rights service at] the housing was great.' (James, 55-64)

Some participants spoke of issues that they had experienced in the past where they felt support from an Ataxia UK service might have helped them deal with a financial issue:

'I got a poor PIP assessment and I didn't appeal because I didn't know how to do it, and what service might help me. I would definitely have benefited there.'
(Robert, 65-75)

Some felt that they would prefer to use a service provided by Ataxia UK rather than other advice services which had not met their needs:

'It would probably be more helpful. The CAB aren't very knowledgeable about ataxia specifically. To have someone to talk to on the phone about it, that would be useful.'
(Liam, 35-44)

Other participants felt that they would prefer to go to other organisations for help, although they still felt Ataxia UK could get involved:

'I would probably go to Scope or Disability UK for help with money issues although Ataxia UK could help with this.'
(Melanie, 45-54)

Participants felt that they might need an advice service in the future, even if they did not currently:

'All is OK so far. I've not needed advice on anything, but I might in the future, I know filling in forms can be quite difficult, and I'd welcome advice on completion at that time. People should be more aware of what's out there, and be more aware of what assessments are going to look at.'
(Hari, 25-34)

'Maybe it's because my ataxia isn't at an advanced stage when I can't work and it impacts on my whole situation, maybe if I was in that situation I would get help.'
(Danielle, 25-34)

Others felt that whilst they were unlikely to need help of this type, either because they were in a reasonable situation, or because they were already familiar with the system, others might benefit significantly:

'There might be others who need the support. I think my needs are only medium, for others they might be high.'
(Ray, 65-74)

'I probably wouldn't need advice about benefits. We have known the system for a long time, but I think a lot of people would need it. We'd be fairly confident of dealing with things because of my son, but it would be valuable for other people to have information about stuff.'
(Rebecca, 45-54)

Some participants felt that though they had other priorities, such a service could be useful for others:

'For me the research is a priority, but if I lived by myself the money would also be important.'
(Sophie, 25-34)

Some participants identified family members as potentially benefiting from Ataxia UK becoming more involved in delivering advice around financial issues:

'It would be worthwhile for Ataxia UK to have a service dealing with this. My son is 31 years of age and he would benefit from that type of support, he would benefit from budgeting advice.' (Robert, 65-74)

Some concerns were expressed about the potential timing of people accessing support from Ataxia UK:

'My fear is that people would already have been looking for benefits at that point. Things would already have been going wrong by the time they got to Ataxia UK' (Kate, 35-44)

Campaigning Work

There were a range of financial areas in which people felt that Ataxia UK could campaign:

'They should pay carers more, what they get is not enough. Carers get more in Scotland, and that is something I think needs to be looked at. People have to give up work to care for people with ataxia, and it all adds up.'
(Graeme, 55-64)

'Jimi' wondered both if he could receive practical help with the issues he was facing around his life insurance, and whether this might be an area in which they could campaign for legal/ policy change:

'Perhaps they could help me with my gripe and ease my stress. Perhaps they could challenge it in some way. Perhaps they could pressure insurance providers to systematically include ataxia, only small numbers would be involved. For someone in their 40s that could make a difference. They would be at the point of having a young family and a mortgage.' (Jimi, 45-54)

Broader Ataxia UK Developments

Participants felt that Ataxia UK had a critical role in improving the provision of information across the different range of ataxias, available to both people with ataxia and those working with them, and the provision of support, again to both people affected by ataxia and those working with them. Those who had been in contact found the organisation helpful.

A consistent theme amongst participants was the need for better promotion of Ataxia UK, and for the dissemination of more information about Ataxia. Awareness of the condition was seen as being much lower than for other more common conditions:

'People need to know what ataxia is. Everyone has heard of cancer or ME or MS, when you say ataxia, they look blank.' (Suzie, 45-54)

'Gary' highlighted the need for more information to be made available to people across a range of settings:

'I think there should be some information in doctors' surgeries. There should be leaflets and information about ataxia like you see about other conditions. There is never anything about ataxia there.' (Gary, 45-54)

'Anne' focused on a specific example of professionals not quite grasping the specific issues faced by people with ataxia that she felt information sharing by the organisation might overcome:

'In general the medical profession doesn't know much about ataxia. When I was in hospital doesn't know much about ataxia. When she broke her hip and had to go to the hospital they were expecting her to be able to walk to the toilet. After you have been in they try and get you up and about. They were saying go and have a shower, that's a big deal for me. They didn't realise that it's difficult for me all the time.' (Anne, 75 plus)

'Graeme' had a similar experience:

'When I go to And E they have to look up my condition. I can see them doing it, though they do it subtly.' (Graeme, 55-64)

Participants also felt there was a role and/ or responsibility for people with ataxia to tell others about the condition.

There was felt to be a lack of services available to people with ataxia:

'I don't feel there is any support with ataxia. When you get cancer, you are given a cancer nurse to call. A lot of people don't call, but knowing someone is there is enough. That would be really valuable, just knowing that someone is there if needed.' (Suzie, 45-54)

'When people get diagnosed I think they get left out in the cold, you get diagnosed and that's it.' (Danielle, 25-34)

'Liam' discussed in some detail the need for wider support, including potentially for professionals:

'It would be good to have a phonenumber with someone to talk to about anything to do with ataxia. It would be useful if we had a counselling service where you could talk to people about any concerns that you have about life. People with young families who were not sure how to deal with it could talk. People could discuss how to talk to families with ataxia.' (Liam, 35-44)

Some participants who were involved in focus groups felt that those groups pointed the way towards potential new activity:

'There should be more groups like thus where we can sit and discuss things.' (Petra, 45-54)

Participants also highlighted a number of other areas in which they felt Ataxia UK could campaign, on the:

- Additional costs associated with ataxia.
- Need for more research, given that the conditions are so rare and research attention is limited.

Section 14: Conclusions and Recommendations

This report has established that people with ataxia face a range of specific financial inclusion needs as a result of their condition.

This final section:

- Assesses the extent to which those needs are currently met by Ataxia UK and the mainstream advice sector, based on the findings of sections 12-14.
- Sets out key themes under which Ataxia UK can organise its response.
- Draws out lessons for future provision from each of the preceding sections.

Sections 11, 12 and 13.

It is clear that many participants had not accessed advice on the financial inclusion issues they were facing when they had needed it, and that many had not been aware of the availability of advice and information that could have helped them deal with those issues. There is an obvious lack of robust and consistent referral routes into financial inclusion advice for people with ataxia, and a lack of sustained effort to reach out to people with ataxia on financial issues.

Those participants and survey respondents who had engaged with mainstream advice services had had mixed experiences. Many had had positive experiences, whether or not those they engaged with have a full understanding of ataxia, whilst others felt that lack of knowledge and understanding of their condition, or simply the general variability of the quality of staff and volunteers working advice services, had led to less satisfactory engagement.

Some participants had received support on financial issues, in particular on benefits from health or social work staff supporting them, but this appears to have been a less common experience, with no sign of a consistent approach being taken.

Participants liked the information, advice and support on other issues provided by Ataxia UK. However, there was no sense from interviewees of engaging with the existing benefits and financial information available on the Ataxia UK website, nor that they were aware of it, nor was there any sense they had accessed information on financial issues through the magazine or at conferences. Survey respondents were generally positive about this information.

It can be concluded that the current provision of information, advice and support to people with ataxia, whether through Ataxia UK itself, or through the mainstream advice sector, is not consistently meeting the financial inclusion needs of those people.

There is therefore a need for action.

There was clear support for Ataxia UK to take some of that action, and a real willingness and appetite to access advice, information and support from Ataxia UK, including from participants who had had broadly positive experiences with other providers.

Participants had a range of more detailed suggestions for what that would involve, and felt that such provision should build on the specific expertise of the organisation in relation to the condition and its deep understanding of the communication and other challenges facing the delivery of information, support and advice to people with the condition.

Five potential areas of activity can be identified for Ataxia UK, which should be potential key themes in a future Ataxia UK financial inclusion strategy. In what follows below, some activities have been identified as actions that Ataxia UK should undertake, and some activities have been identified as actions that Ataxia UK should consider or that it might undertake.

In terms of information, advice and support:

- Ataxia UK should develop, and disseminate more vigorously and more effectively, more information about the financial inclusion issues facing people with ataxia, on its website, in emails, in magazines, at conferences, and where necessary in printed format.
- It should also become more involved in the direct provision of advice, on the lines of the proposed partnership with Scottish Huntington's Association, or by itself, through online, telephone and if, resources were to allow, face to face channels.
- Geographical and resource constraints mean that Ataxia UK will face significant barriers its ability to deliver face to face support, and more intensive forms of remote support. It should therefore also work to strengthen the engagement of people with ataxia with mainstream advice provision, through providing information about such provision, and developing referral routes into such provision. Ataxia UK should support the improvement of such services through the provision of information about the condition relevant to advice providers, training, guidance, and second tier support. It should also consider whether there is a role for delivering complementary remote advice alongside mainstream advice workers during appointments.

Information, advice and support services have to work within existing benefit and other systems. People with ataxia would benefit from improvements in those systems. Ataxia UK should therefore seek to:

- Offer information, training and advice to those working in the benefit system and the financial industry to develop their practice so that they are better able to meet the needs of people with ataxia.
- Campaigning to change practices, policies and legislation within which those working in the benefit system and the financial industry operate to ensure that the needs and specific circumstances of people with ataxia are better considered and met, using data from its engagement in provision.

Section 3- Experience of Diagnosis.

The most striking aspect of participants' experience of diagnosis was its variety; in terms of the age at which it was carried out, the time taken from onset of symptoms/ whether symptoms had appeared at that point, and the trigger for diagnosis.

Each of these differences carries implications for the financial challenges faced by people with ataxia, and therefore the response:

- Those diagnosed earlier in their working life are likely to experience more disrupted employment, greater financial impacts, greater risk of debt, and a greater need to plan for the future.
- Those diagnosed later in life may face specific issues around access to appropriate retirement age benefits and the dual challenges of ageing and ataxia.
- People may dip in and out of engagement with ataxia focused services as their condition progresses, financial issues may be a useful bridge back to services.
- The gap between diagnosis and serious symptom onset creates an opportunity for financial planning for some people.

Section 4: Impact on Daily Life

The impact of ataxia on participants' and respondents' mobility, energy, speech and communication and ability to carry out daily tasks makes clear that people with ataxia will almost always be entitled to disability related benefits, PIP, DLA or AA, at some point, and potentially to benefits for people unable to work due to disability. Ataxia may also have significant impact on people's mental health, again directly relevant for entitlement to disability related benefits.

Ensuring that people with ataxia understand in detail the relationship between the impact of the condition and its progression and their benefit entitlement should therefore be a major priority for Ataxia UK.

Any services delivered by Ataxia UK must reflect the specific communication and access challenges experienced by people with ataxia

Finally, any work on financial issues must acknowledge the situation of those who take up caring responsibilities for someone with ataxia, particularly where household incomes are affected if they have to give up work. Information, advice, support and links to other services for carers have an essential place in the Ataxia UK response.

Section 5: Employment and Housing

The impact of ataxia on the experience of participants and respondents in the labour market was stark, with many losing employment, or not able to progress in work as they had planned, and some leaving the labour market sooner than planned due to being unable to find new, more suitable employment. Some had experienced discrimination at the hands of their employers as a consequence of their condition.

There are also clearly a range of specific financial aspects to making decisions relating to maintaining, seeking and retiring from employment.

Ataxia UK should consider how it can ensure that people with ataxia benefit from information, advice and support around:

- Employment rights, in particular around constructive dismissal and reasonable adjustments.
- Finances and planning, including the appropriate timing of retirement to maximise pension rights.
- Sources of Government assistance to remain in work, for example Access to Work.
- Options for continuing employment part time, education and training and volunteering.

Employers would also potentially benefit from information to support their fulfilment of responsibilities, and to understand better the nature of the condition.

Housing is also clearly a significant issue for a minority of participants who find their current housing is not fit for purpose.

Ataxia UK should consider how it can ensure that people with ataxia benefit from; access to information; advice and support focused on housing rights, housing options and aids and adaptations, in particular on how to access to appropriate social housing; and on planning ahead for possible moves and adaptations if they are owner occupiers.

Section 6: Financial Situation.

As suggested above, there is significant variety in the financial experiences of people with ataxia. Some experience very much more financial pressure than others. There is an association between financial pressure and experience of ataxia at a younger age due to the employment impact of the condition, and between financial pressure and having worked in lower waged employment. Many of those impacted by ataxia after a lifetime of well paid employment do not face significant financial difficulties (although advice about benefits may still be useful for them.)

Money problems can be a source of significant stress.

- Being on a low income is inherently stressful, although many people with ataxia do accustom themselves to living on lower incomes.
- Those who were previously higher paid may struggle financially and emotionally if their loss of employment was more sudden than expected or not planned for.

Ataxia UK should:

- Ensure that information, advice and support for people with Ataxia reflects this variety of experience.
- Be prepared to prioritise some groups, and accept that specific areas of work should be a higher priority than others.
- Understand that even in the absence of the resolution of the problems they face, many people with ataxia will benefit from talking through their financial problems, with peers, volunteers or professionals.

Section 7: Additional Costs.

Many people with ataxia clearly face significant additional costs due to their ataxia associated with mobility, aids and adaptations, treatments, purchase of support/ care, and daily living.

People with ataxia should have access to information, advice and support so they are aware of, and can access benefits, other financial and in kind support from the state to cover these costs as far as possible.

The evidence from this report also suggests that Ataxia UK should continue to support people with ataxia directly through grants.

Ataxia UK might also consider:

- How it can assist people to access information about cheaper deals on household basics.
- The potential for peer information/ peer support to help people find cheaper specialist goods and services.
- The possibility of facilitating bulk purchasing to reduce costs for people with ataxia. This might be something as simple as facilitating and setting up physical activity sessions to complement or reduce reliance on private physiotherapy.
- How better information about mitigating treatments and appropriate self care might reduce the risk of people wasting money on ineffective treatment.
- The possibility of online provision of group physiotherapy sessions.

Section 8: Benefit Issues.

The impact of ataxia on people's daily lives and on the costs they face means that access to disability related benefits will be critical. Participants' and respondents' experiences suggests that information, advice and support will be required at every stage of engagement of people with ataxia with the benefit system if they are to take up their full entitlement, from becoming aware of entitlement and deciding to apply, to initial application and form completion, assessment, and pursuit of reconsideration/appeal.

Awareness of entitlement

Those who have yet to engage with the benefit system need access to accurate information about their potential entitlement to different benefits, and how their condition relates to and triggers that entitlement, and for that information to encourage them to start an application where relevant. Stigma related concerns about applying for benefit may also mean that they need encouragement, or in some sense permission to do so.

Ataxia UK has a number of existing routes for communication with people with the condition that it can fully utilise to disseminate this information. It is also clear that diagnosis, and ongoing engagement between people with ataxia and neurology services, offers the opportunity for communication of some of this information, or direction towards it, if neurology services have sufficient awareness of benefit issues.

Alongside information about benefit entitlement people with ataxia need information about advice and support available to them to help them with their application, or need to be referred to such advice and support through established referral routes.

Initial applications

Ataxia UK should ensure that during initial applications people with ataxia can benefit from:

- Information about how application forms should be completed and what decision makers are looking for.
- Advice and direct assistance with form completion, including handwriting forms on their behalf, and collation of supporting evidence.
- Support to deal with the emotional aspects of considering the impact of their condition and to deal with the DWP over the phone, including others acting as their agents when doing so.

Before and during assessments

Ataxia UK should ensure that before and during assessments people with ataxia can benefit from:

- Accurate information about how assessments are organised, the ground that will be covered, and their rights at assessments, to assist people to prepare, and to reassure them that the stories of the worst cases of treatment within assessments that circulate within communities are not typical.
- Support to prepare for an assessment, including preparation in relation to key issues around health impact that need to be covered.
- Support within the assessment; moral support; practical support in ensuring that key impacts on their health are fully explored; assisting communication; and at the request of the person with ataxia, speaking on their behalf. This can also ensure that good practice and the rights of benefit claimants are respected within assessment processes, and challenge assessors where they are not.

Appeal and reconsideration

Ataxia UK should ensure that after a negative decision people with ataxia can benefit from:

- Information about the grounds on which appeals and Mandatory Reconsiderations can be based, and the process for requesting reconsiderations and pursuing appeals.
- Support to prepare a submission and documentation for a Mandatory Reconsideration or an appeal.
- Support at an appeal, whether in the form of moral support, or through formal representation.

Changing practice

It is critical that those working in the benefit system, whether they are assessing claims or carrying out assessments, or dealing directly with people with ataxia understand the impact of ataxia on the lives of claimants in terms of mobility, ability to carry out daily tasks, communication and mental health. That understanding should include awareness that some of the impacts of ataxia might not be immediately visible, and that completion of forms might be difficult for people whose handwriting has been affected by ataxia.

Ataxia UK should also consider how it can:

- Work with the DWP and contracted providers to better inform and shift the practice of decision makers and assessors so that the impacts of the condition on the lives of people affected are better understood, assessments are carried out more appropriately and decisions are more reflective of their lived reality.
- Campaign for appropriate changes to relevant social security legislation, with a particular focus on issues around reassessment for people with progressive conditions.

Section 9: Debt and Money Management

Problem debt appears to affect only a small minority of people with ataxia, and the debts that affect those people appear to be generally associated with core household bills. Heavy borrowing does not appear to be widespread. However, there is clearly a risk at the time of any loss of employment of previously affordable borrowing becoming unaffordable, and rates of experience of debt amongst survey respondents using consumer credit are quite high.

Ataxia UK should:

- Provide basic information through all its channels on debt and debt remedies.
- Provide information about sources of mainstream advice to people with ataxia facing debt issues, and develop referral routes with those sources of advice.
- Ensure that any staff employed in its own, or partnership based advice services, can deliver basic debt advice, including reviewing income and expenditure, ensuring clients are aware of rights and responsibilities, and making contact with creditors for core debts on their behalf.

It should also work with providers of debt advice to ensure that the needs of people with ataxia seeking help with debts are understood.

It is clear that people with ataxia do not need general advice and support to manage their money, and that the offer of such would not be taken up by people who already broadly consider themselves financially capable.

Action from Ataxia UK in relation to money management would pick up on some of the suggestions which followed discussion of the findings of section 8, but should also include:

- Direct provision of basic information on budgeting/ budgeting and money management guides, perhaps including money management tools adapted to people with ataxia.
- Linking people to appropriate information, guides and tools provided by others.

Section 10: Financial Products and Planning

Levels of forward financial planning by people with ataxia specifically focused on the condition are lower than might be expected given the long term nature of the condition and its potential impact on employment and incomes. This appears to be partly explained by the late onset of the condition for many people, which means that key financial decisions have already been taken by the time of diagnosis or impact of their condition, but also by attitudes to the future which are common in the general population; there is little sense that people with ataxia are more aware of future financial issues. It is also the case that some people with ataxia have lived for the longer term on incomes low enough to make financial planning seem less relevant. Where people with ataxia have planned ahead financially, whether this has been influenced by their condition or not, there appear to be clear benefits from doing so.

In terms of the provision of information, advice and support Ataxia UK should:

- Promote the value of forward financial planning for people with ataxia.
- Directly provide information about financial planning relevant to the specific financial issues faced by people with ataxia.
- Link people to information about financial planning provided by other organisations, both mainstream organisations, and other organisations working with disabled people/ people with progressive conditions.
- Provide information about the interaction of pensions, savings and the benefit system to guide people in their financial decision.

There appears to be value in people with ataxia accessing independent financial advice, but experiences of IFAs are mixed and there is uncertainty about the quality of such advice for people with ataxia.

Ataxia UK could respond by:

- Offering training and information about ataxia to IFAs so that they can be more effective in tailoring their advice to the needs of people with ataxia.
- Providing a forum for people affected by ataxia who have used IFAs to share information about their experience.
- Considering a kitemark scheme for IFAs who have gone through training identifying them as having a certain level of knowledge about ataxia.
- Considering whether more formal partnership working with IFAs might be possible.

Ataxia UK should also:

- Consider how it can promote better understanding within the insurance and general financial industries that ataxias are often not terminal conditions, and that many people die with ataxia rather than because of ataxia.
- Seek to explore further barriers to accessing life and critical illness insurance for people with ataxia, and work with the insurance industry and potentially with Government to ensure that people with ataxia do not face unjustifiable barriers and costs in accessing such provision.