Transparent or opaque? Disabled people in Scotland describe their experience of applying for Disability Living Allowance.

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What is This?
Transparent or Opaque?
Disabled People in Scotland Describe Their Experience of Applying for Disability Living Allowance

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Abstract

• Summary: Disability Living Allowance (DLA) is a UK social security benefit designed to meet the extra costs associated with disability. It has been suggested that some people with disabilities who are eligible for DLA do not claim the benefit, and amongst those who do claim there are inconsistencies of award decision-making. The aim of this research was to establish the level of knowledge relating to DLA amongst disabled people in Scotland and to explore the process of application from the perspective of those involved. Questionnaires were distributed through voluntary organizations. Six hundred and six completed questionnaires were received.

• Findings: Almost all respondents (97%) found the form difficult to complete. Many respondents indicated that they could not have completed the forms themselves, particularly those with learning disabilities, mental health problems and/or difficulty concentrating. Many applicants believed that decisions were inconsistent and often based on inadequate understanding of individual circumstances. A significant number of applicants (42.9%) who were subsequently awarded the benefit were turned down on their first application.

• Applications: The findings of this study suggest that the Scottish Parliament should ensure that disabled people have access to advice and guidance about welfare benefits irrespective of whether potential applicants are in contact with social work departments. More generally, the findings prompt questions about how the additional costs associated with disability are managed elsewhere. Social workers should be proactive in providing information and advice relating to welfare benefits in Scotland and in other countries.

Keywords benefits disability information social exclusion
Introduction

Disability Living Allowance (DLA) is a social security benefit designed to meet the extra costs associated with disability that are experienced by people who have care or mobility support needs. Receiving DLA may be seen as an acknowledgement that a person is disabled under the terms of the Disability Discrimination Act (1995), and can be a ‘passport’ to other benefits. However, the application process has been found to be time consuming and can leave claimants and their carers feeling frustrated and demoralized.

Disability impacts upon the lives of a great many people in Scotland today. Of a population numbering a little over 5 million (Randall, 2002) it is estimated that 800,000–900,000 are people with a disability (Riddell and Banks, 2001; Grewal et al., 2002) and a further 600,000 are impacted upon by disability in their role as a family member and/or as an informal carer (Scottish Executive, 2003b). It is understood that the standard of living of people with disabilities is often lower than that of the general population. For example, the research literature describes various attributes of this population in relation to the costs associated with living with a disability on a day-to-day basis, levels of employment and standard of living:

- Particular daily costs are associated with living with a disability. These costs include heating, laundry, clothing, special diets, travel, prescriptions and equipment (Berthoud, 1998: 45).
- Levels of unemployment are higher amongst people with a disability than amongst the general population (Knight et al., 2002: 27), although it should be noted that there are some signs that this situation is changing (Berthoud, 1998: 62).
- The standard of living is low, with 75 percent of people with a disability depending upon benefits as their main or only source of income (Daly and Noble, 1996; Knight et al., 2002).

The award of DLA to a person or family with a low standard of living can make a considerable difference to their financial status. Not only can the award itself constitute a substantial increase to the household’s income, but as a ‘gateway’ to other benefits, for example Working Tax Credit and Child Tax Credit, it has the potential to have an even greater positive impact on standard of living. Consequently, appropriate and equitable award of the DLA is essential to ensure that those most in need receive the financial assistance they require.

Background

In the mid-1980s the Office of Population Censuses and Surveys carried out a series of disability surveys (Martin et al., 1988). The Government of the time responded with the publication of *The Way Ahead: Benefits for Disabled People*
Department of Social Security, 1990), which marked the introduction of the DLA and the revision of the Attendance Allowance (AA). The DLA had three core aims:

1. To meet the extra costs associated with living with a disability;
2. To widen the scope, or reach, of former benefits by introducing lower rates of benefit, i.e. people with ‘milder’ disabilities would be entitled to the benefit;
3. To allow people with a disability to make a self-assessment, i.e. to describe their disability and their experience of its impact upon their daily life in their own terms.

Importantly, the benefit is not means tested, it is not subject to tax and employment status does not affect the amount of award (Berthoud, 1998: 50).

Structure of DLA

To better understand the complexity of the DLA itself, the difficulties associated with the application process and the controversies surrounding the perceived inequities of award of the benefit, it is necessary first to look at the structure of the benefit itself. The DLA is comprised of two components: personal care and mobility needs. This structure is derived from its precursors the Attendance Allowance and Mobility Allowance. An applicant may apply for either component separately or for both components. The care component is payable at one of three rates: higher, middle or lower, whereas the mobility component is payable at one of two rates: higher or lower. Applicants may be awarded any rate of the care component combined with either of the mobility component rates. This results in six possible combinations of award. In addition, either component may be awarded separately at any of the applicable rates: this results in a further five possible award levels. Ultimately, the DLA may be awarded at one of eleven different rates. Understandably, much of the criticism that surrounds the DLA relates to the complexity of its structure (Daly and Noble, 1996: 38) – the likelihood of error of application, administration and adjudication are considerably increased due to the complexity of the rules and guidelines associated with the benefit (Hirst, 1997: 137). To qualify for DLA the need for help must have existed for three months and be expected to last for at least a further six months.

A central feature of DLA is that it enables the claimant (or their advocate) to describe the nature of their disability and its impact on their daily lives. This is seen to be particularly important where a disabling condition is fluctuating in nature or is subject to remissions and exacerbations (Hirst, 1997: 138). The claimant is able to provide up to two supporting statements – one from a friend or relative, the other from a professional such as their general practitioner (GP). At the administrative end of the process, adjudication officers are able to request further information from the claimant, from the claimant’s GP or from...
a doctor contracted to the Benefits Agency (now the DWP Disability and Carers Service), i.e. an examining medical practitioner (EMP).

Internal review and the right to appeal are integral to the design of the DLA. At appeal, claimants may be accompanied by, or represented by another person such as a friend or relative, or a professional with experience of tribunals, such as a disability Welfare Rights Officer.

What is evident from a consideration of the structure, the application process and the award process of the DLA is that it is based upon the medical model of disability, in spite of the Government’s stated aim of taking on board the views of the organizations representative of people with disabilities (Daly and Noble, 1996: 40). Critics of the structure and the application and award processes maintain that the medical model is inappropriate in this context. Rather the social model, or at least a model which combined elements of the two, would be both more appropriate and more effective in addressing the ‘care’ and the mobility issues that impact upon the daily lives of individuals with disabilities. Applying the medical model implies that the person with a disability requires financial compensation to enable them to function within the existing constraints of contemporary society and contemporary environments. What it does not allow for is change: change in service delivery, change in environments relevant to the individual, or a shift towards the ‘consumer’ perspective rather than continuing to impose the paternalistic medical model: neither does it adopt an individual, holistic perspective (Noble et al., 1997: 750).

Problems Associated with the Uptake of DLA

When the DLA was first introduced the Benefits Agency was unable to cope with the volume of applications due to the overwhelming success of the publicity campaign that had preceded its launch. However, although initial uptake of DLA far exceeded original forecasts there remains some concern that many people with disabilities who are eligible for DLA do not claim the benefit and amongst those who do claim there are apparent inconsistencies of award decision-making (Noble et al., 1997: 747). Recent studies (Ward, 1995; Daly and Noble, 1996) have described some of the problems associated with the DLA claims process and with subsequent reviews and appeals.

Lack of information regarding the existence of the benefit and ignorance of or misconceptions concerning the criteria for eligibility are the first notable barriers to application. Subsequent to the initial launch, the most frequently cited sources of information about the benefit are ‘casual’ sources such as friends and relatives, with only 10 percent of claimants having discovered about the benefit through their GP or GP surgery (Ward, 1995; Hirst, 1997).

The next stage of the process involves completing the application form. Many claimants describe this as a daunting experience. Specific problems with the content and layout are cited but people also find it difficult to describe how their disability affects their daily life. There is a tendency to describe one’s
disability and the experience of disability in a more positive light than reality might warrant (Ward, 1995: 12–17); this is associated to a certain degree with the desire not to consider oneself as ‘disabled’ (Hirst, 1997: 138). Research seems to indicate that claimants are more successful if they receive professional or ‘informed’ assistance with the application form itself. With regards to the provision of one or two statements of support, studies have been inconclusive: Ward (1995: 17) found that applications were more likely to be successful where at least one statement of support had been provided, whereas Hirst (1997: 141) found claims to be less successful where a supporting medical statement was provided, except with regard to the mobility component.

Unsuccessful claimants may ask for a review of their application, i.e. they may appeal against the initial decision. Ward’s study (1995: 15) showed that 60 percent of unsuccessful DLA applicants appealed or stated an intention to appeal, but 25 percent of those who replied in the negative to this question did so because they were unaware that they were able to ask for an appeal. The appeal process itself was marked by a lack of information. Of those who applied for an appeal 50 percent were unaware that there would be a tribunal. Additionally, appellants reported that the tribunal documentation was difficult to understand. Appeals were most likely to succeed if the appellant or their advocate attended the tribunal. The ability, or not, to travel to a tribunal was reported as a barrier to attendance as was access to the tribunal building (Ward, 1995: 19).

Overall satisfaction with the DLA application and award process was strongly associated with the outcome result, i.e. those who received the benefit were most likely to be pleased with the process (Ward, 1995: 19).

**Problems Regarding Award Decision-making**

Government policy makers aim to ensure that public funds are dispersed appropriately, equitably and to the areas (or populations) of greatest need. Yet Hirst (1997: 137) found that DLA claims and outcomes varied for people with similar needs between regional Disability Benefit Centres. Notably, Scottish claimants were more likely to be unsuccessful than their counterparts (i.e. claimants with similar needs) in other regions, whilst being part of a group described as ‘some of the most deprived and vulnerable people in society’.

**Uptake of DLA in Scotland**

During February 2003, 273,700 people in Scotland were receiving DLA (Scottish Executive, 2003a). This figure, at 5 percent of the total population, is higher than the UK as a whole, which has a rate of 4 percent. However, even within Scotland the proportion of the population in receipt of DLA varies markedly between local authorities, e.g. 3 percent in Moray, Perth and Kinross, and East Renfrewshire; 7 percent in Inverclyde, North Lanarkshire, and West Dunbartonshire; and 8 percent in Glasgow City.
Almost two-thirds (65%) of those in receipt of DLA in Scotland received both care and mobility components, just less than a quarter (24%) received only mobility component, and just over one in ten (11%) received care component only.

Impact of DLA on Low-income Households

A key feature of the DLA is that it constitutes a ‘gateway’ award, i.e. it is the means by which claimants gain access to additional benefits, whilst the award itself may constitute a substantial increase in an individual’s or a household’s income (Noble et al., 1997: 748). Studies have shown that, although the award is designed, in part, to compensate for the extra costs associated with daily living, in reality it is used to cover basic daily living costs (Horton and Berthoud, 1990; Noble et al., 1997). Consistency of decision-making and award is vital due to the considerable positive impact a successful claim has on the claimant’s standard of living (Hirst, 1997: 148).

The Study

In light of the difficulties identified above and anecdotal reports from members, a sub group of Disability Agenda Scotland (DAS)² carried out a survey during 2001/2002 which sought to explore the nature and extent of people’s knowledge of Disability Living Allowance, and what their experiences were when making a claim.

Aim

The study’s aim was to establish the level of knowledge relating to DLA amongst disabled people in Scotland and to explore the process of application from the perspective of those involved.

Specific Questions Addressed

• Are disabled people in Scotland aware of DLA and if so, how did they find out about it?
• How easy do people find it to apply for DLA?
• If seeking help to apply for DLA who do people approach, and how satisfied are they with the support they receive?
• How many people who receive DLA have to make a renewal claim, and how many have their DLA reviewed?
• What are people’s experiences of making a renewal claim or having a review?

Method

Questionnaires were distributed through a variety of channels including local branches of member organizations of Disability Agenda Scotland. It is not
possible to know exactly how many questionnaires were sent out as some may
not have reached the target population and others may have been duplicated
in order to reach a larger audience. Altogether, 606 completed questionnaires
were received.

Respondents
In some instances, questionnaires were completed on behalf of others, for
example for young children, or people with severe and complex needs. Of the
respondents, 339 (55.9%) were male, 247 (40.8%) were female, and gender was
not known for 20. Ages ranged from pre-school aged children (<5) to indi-
viduals in their seventies. Figure 1 shows the age and gender of respondents.

Inspection of Figure 1 reveals that almost half the respondents were aged
35–54, a slightly higher proportion in almost all age groups being male. Four out
of ten respondents (38.1%) reported that they lived alone. Just over a quarter
of respondents (27.6%) reported that they had more than one impairment.

Of the 606 people who completed the questionnaire, 528 respondents
(87.1%) reported that they had applied for DLA, 476 of whom (90.2%) were
currently receiving it. Those who reported that they had not applied were asked
why they had not done so. Twenty-seven, a third (34.6%) of those who had not
applied for DLA, reported that they did not think that this benefit applied to
them, eight reported that they did not need any help, three thought that they
could not claim because they were working, and one thought that the money
they already had was too high for them to be eligible. Eight indicated that they
had ‘other’ reasons for not applying.

Responses

Are disabled people in Scotland aware of DLA and if so, how did they find out
about it? More than nine out of ten respondents (93.2%) reported that they
had known about DLA prior to receiving the questionnaire: forty respondents

![Figure 1](attachment:image.png)
(6.6%) had not been aware of this benefit. When asked to indicate from a list of potential sources of advice how they had found out about DLA, 148, a quarter of all respondents (24.4%), reported having found out about it from social work. The next most frequently used source of information was family and friends (17.8%), followed by voluntary organizations (17.6%). Sixty-six respondents (10.9%) reported having found out about DLA from the Health Service including community psychiatric nurses and hospitals. Forty-four (7.3%) found out about DLA from the Benefits Agency, and ten (1.7%) from the Citizens Advice Bureau. Sixty-seven respondents (11.1%) reported having found out about DLA from ‘other’ sources, e.g. support workers, teachers, and the media. Overall there appeared to be no definitive source of information about benefits, as one respondent explained: ‘I only found out about DLA by talking to my friends who were already claiming it.’

How easy do people find it to apply for DLA? Of those who had applied for DLA, 514 respondents (97.3%) reported that they had found the form difficult to complete. Of these, 426 (82.9%) got someone to help them and 86 (16.7%) managed to complete the form themselves. Fifteen respondents reported that they had found the form easy to fill in and three could not remember. Of those who found the form difficult to fill in, 214 respondents (41.6%) reported that they did not understand the questions:

The DLA forms are like negotiating a minefield. I think a lot of the questions are ambiguous and misleading and designed to make it difficult for the applicant to fill in . . .

Several respondents thought that the form was too long, and others felt that the forms were geared towards people with physical disabilities and that they were not always appropriate for people with mental health problems or sensory impairments. Thirty respondents indicated that they had found the questions repetitive:

Information had to be repeated constantly for each section – found this irritating . . .
I am deaf/blind with quadriplegia – surely this is self-explanatory.

Twelve respondents indicated that the instructions were not clear and that questions seemed to contradict each other:

It was difficult knowing which questions did actually apply to me, and what type of information the agency was looking for.

Eleven respondents found it difficult to make their situation ‘fit’ the questions, particularly those with mental health problems or learning disabilities:

Couldn’t fit my difficulties into number of times/day . . . doesn’t work like that.

A number of respondents reported that they tried to focus on the positive aspects of their situation and thus found it very distressing to complete the form:
I found it hard to describe how ill I can become, and putting these feelings and fears into words can be very hard . . . as well as finding the whole process distressing.

Many respondents indicated that they could not have completed the forms themselves, particularly those with learning disabilities, mental health problems and/or difficulty concentrating. Parents and carers also found the forms difficult and in some instances distressing:

Hard to understand exactly what is being asked – [I am] not a qualified doctor or psychiatrist or lawyer.

Some claimants were conscious of how much of other people’s time was involved in helping them:

As I have severe learning disabilities – I think that DLA should be given automatically as people like me have to depend on someone else filling in the forms and parents/carers have enough to do without the hassle of claiming DLA.

If seeking help to apply for DLA who do people approach, and how satisfied are they with the support they receive? Overall, 143 respondents, a third (33.1%) of those who received help with their DLA application, received help from social workers. Almost one in three (29%) reported having received help from a voluntary organization, one in five (19.2%) from family and friends, one in seven (13.8%) from health professionals including their GP or Health Visitor, and just over one in ten (11%) received help from a Welfare Rights Service. Fifty-three respondents (12.4%) reported having received help from another source, e.g. support workers, job coach, and carers. Less than one in five reported having received help from the CAB, the Benefits Agency or the Benefits Enquiry Line.

Overall, the majority of respondents reported having been happy with the help received. For example, almost four out of five respondents (79%) who received help from social workers, and three-quarters (75.8%) of those who received help from voluntary organizations reported that the support they received had been good. Respondents who had sought support from voluntary organizations that provided benefit advice were particularly satisfied with the support they received.

However, amongst the small number of respondents who had approached the Benefits Agency (19) or Benefits Enquiry Line (19), satisfaction was lower: only four out of ten respondents reported that the support received was good (41.2% and 38.1% respectively). Difficulties included not being able to contact them by telephone, poor communication, and a lack of understanding of their disability:

I believe people employed in Benefits Agency who make final decision should have some medical knowledge or understanding of grades of disability.
Outcome of DLA application As mentioned above, almost 476 respondents (78.5%), nine out of ten of those who had applied for DLA (90.2%), were receiving it when they completed the survey. When asked what rate they received, 138 respondents (29% of those in receipt of benefit) reported that they had been awarded the higher rate of care component, 150 (31.5%) the middle rate and 69 (14.5%) the lower rate. Of respondents in receipt of the DLA, 128 (26.9%) reported that they received the higher rate of mobility component, and 200 (42%) received the lower rate. Some respondents indicated that they were not sure what level of award they received and a number failed to complete this section. Table 1 shows the number of respondents who reported being in receipt of different combinations of care and mobility components. Inspection of the table reveals that a slightly higher number of respondents reported that they received DLA care component than mobility component. Ninety-nine respondents (20.8% of respondents in receipt of DLA) reported that they received only a care component and 70 (14.7%) received mobility only: 258 (54.2%) received a combination.

Duration and perception of level of award Two hundred and fifty respondents, more than half of those in receipt of DLA (52.5%), reported that their award was for life/indefinite. One respondent had received their award for ten years, one for seven years and one for six. Forty-six respondents (9.7%) reported that they had received their awards for five years, twenty-two (4.6%) for three years, eighty (16.7%) for two years, and five for one year.

Table 1 Level of award reported by respondents in receipt of DLA*

<table>
<thead>
<tr>
<th>Care component</th>
<th>Lower mobility component</th>
<th>Higher mobility component</th>
<th>Total combined mobility and care components</th>
<th>No mobility component (care only)</th>
<th>Total combined mobility and care components</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lower</td>
<td>26</td>
<td>8</td>
<td>34</td>
<td>35</td>
<td>69</td>
</tr>
<tr>
<td>Middle</td>
<td>94</td>
<td>10</td>
<td>104</td>
<td>46</td>
<td>150</td>
</tr>
<tr>
<td>Higher</td>
<td>29</td>
<td>91</td>
<td>120</td>
<td>18</td>
<td>138</td>
</tr>
</tbody>
</table>

* Excludes those who did not complete this section or were unsure of levels.
One hundred and thirteen respondents, almost a quarter of those (23.7%) in receipt of DLA, reported that their award had been lower than expected:

My experience has not been a good one. Three forms which had been filled in went missing . . . Eventually when I was awarded DLA I received Care component only although I did previously receive Mobility component also . . . I have since re-applied . . . it has been a lengthy and disappointing experience.

However, 65 respondents (13.7%) reported that their award had been higher than expected. One respondent drew attention to the implications of receiving DLA, which is sometimes seen as an acknowledgement of disability, and thus the level of award can affect other benefits:

Attention desperately needs to be paid to the fact that you can only get high rate DLA if you have night time needs. You can only get Independent Living Fund if you get high rate DLA. Therefore people with very high daytime needs don’t get it because they sleep at night.

Multiple applications Two hundred and seventy-three respondents, almost six out of ten (57.1%), reported having been awarded DLA on their first application. One hundred and twenty-four, just over a quarter (26.1%), reported having been awarded DLA on their second application, while 46 (9.7%) reported having submitted more than three applications before being successful. Thirty-four respondents in receipt of DLA (7.2%) were unsure how many applications they had made prior to being successful.

Many respondents reported that their first application was not successful, or that they were awarded a lower level of benefit than they believed they should have:

I was devastated when they turned down my initial claim for my daughter. The form had been so heartbreaking to complete and my daughter has been diagnosed with a recognized disabling terminal illness. I was almost too upset to appeal.

There was a perception that few people are successful the ‘first time’, and many applicants have to appeal:

I heard that they turn everyone down first time, no matter what the circumstances.

Seeking assistance Respondents who had accessed assistance when completing their application for DLA were asked who had helped them. Table 2 shows the sources of assistance used and the proportion of respondents who were successful in being awarded DLA following their first, second or third-plus application.

Inspection of the table confirms that, overall, nine out of ten respondents (89.2%) who had applied for DLA had been awarded it eventually. However, more than four out of ten (42.9%) of those who were subsequently awarded the benefit were turned down on their first application. Of those who applied a second time, almost four out of ten (39.2%) were again unsuccessful. Forty-six respondents, almost one in ten of those who were ultimately awarded DLA
(9.7%), were required to complete three or more applications. A further 44 were not receiving DLA at the time that they completed the questionnaire.

Unfortunately we do not know at what point applicants sought assistance in completing their forms, for example if they tried on their own the first time, and sought assistance if they failed, or if they sought assistance with their first application. A number of respondents had sought advice from more than one organization:

I first applied through the Citizens Advice Bureaux. They were not very professional and [I] was unsuccessful. I then applied through the housing support team and got the low rate in both care and mobility.

Six out of ten (60.4%) of those who managed by themselves, or found the form easy to fill in were awarded DLA following their first application, and a quarter (24.8%) were successful on their second application, a level of success which compares favourably or exceeds those who sought assistance from organizations that would be expected to ‘know the ropes’. The figures from this study suggest that success is a lottery and may rest on persistence as much as strategy.

Table 2  Source of assistance when completing application for DLA*: number of applicants seeking assistance by source of support, proportion awarded benefit and proportion successful following 1st, 2nd or 3+ applications

<table>
<thead>
<tr>
<th>Source of assistance</th>
<th>No. and % of applicants seeking assistance (n = 426)</th>
<th>Proportion submitting 1, 2 or 3+ applications prior to being awarded DLA</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>Social work</td>
<td>143</td>
<td>124</td>
</tr>
<tr>
<td>Voluntary organizations</td>
<td>124</td>
<td>101</td>
</tr>
<tr>
<td>Family and friends</td>
<td>82</td>
<td>80</td>
</tr>
<tr>
<td>Welfare rights</td>
<td>47</td>
<td>42</td>
</tr>
<tr>
<td>GP/health visitors</td>
<td>33</td>
<td>29</td>
</tr>
<tr>
<td>Other NHS</td>
<td>26</td>
<td>19</td>
</tr>
<tr>
<td>Benefits Agency inc. Benefits Enquiry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Line</td>
<td>25</td>
<td>22</td>
</tr>
<tr>
<td>CAB</td>
<td>19</td>
<td>19</td>
</tr>
<tr>
<td>Other</td>
<td>53</td>
<td>46</td>
</tr>
<tr>
<td>No help needed</td>
<td>101</td>
<td>94</td>
</tr>
</tbody>
</table>

* Some respondents cited more than one source of assistance.
Medical visits

One hundred and fifty-seven respondents, just over a quarter (25.9%), reported that they had been assessed by an EMP. Half of all respondents with a physical disability (50.7%) or dual sensory impairments (48.3%) received a medical visit. A lower proportion of respondents with a learning disability (37.1%) or mental health problems (23%) reported having been assessed by an EMP. No association was found between likelihood of receiving a medical visit and age or gender. Further investigation showed that a higher proportion of respondents who had a medical assessment were awarded higher level mobility component (p<.000). Just over half the respondents (53.7%) who had received a medical visit were awarded higher level mobility component, one-third (33.3%) were awarded lower level and the remainder were not sure of the level they had been awarded. However, less than half (47.9%) the respondents in receipt of higher level mobility component reported having had a medical visit, which suggests that a medical visit was not mandatory for individuals applying for the higher level mobility component. No association was found between having had a medical assessment and level of care component.

Satisfaction with medical visit

When asked if they had been happy with the EMP’s visit, six out of ten (60.5%) of those who had received an assessment reported that they had been. Respondents who reported that they had not been happy with their medical assessment (54) were asked to indicate why not. Thirty-five, almost two-thirds (64.8%), thought that the doctor did not understand their disability; fourteen, just over a quarter (25.9%), reported problems communicating with the doctor – four of these claimed that there was no interpreter present – twelve (22.2%) reported that they did not have a carer present, and that the visit was rushed.

Renewal or review

Two hundred and seventeen respondents, just over one-third (35.8%), reported that they had made a renewal claim. Of these, 56.2% reported that the level of their award had stayed the same, 10.6% were reduced, and a similar proportion stopped (9.7%). Thirty respondents reported that their award had been increased following their application for renewal. More than half (51.2%) were awarded DLA for the same duration as before, twelve awards were lengthened and seven shortened.

Respondents also drew attention to the difficulties experienced when re-applying due to changed circumstances. However, others felt that they had to reapply every few years with no expectation of change which they found hard to cope with:

I’ve had to re-apply every three years, although my daughter wouldn’t get any better . . . I used to dread when it came to re-applying, especially the repeated questions and how long everything took to do.

In some cases the time taken to process such applications could lead to considerable hardship. Having applications turned down and then appealing
means that claimants may not receive a final outcome for some time. Respondents claimed that the stress of completing an application and then having to appeal could make their condition worse. One respondent explained:

I found it a very traumatic and nerve racking experience. It made my epilepsy and other conditions worse, until I heard from the DLA when I was refused and had to appeal, I was really upset . . .

Several respondents indicated that they were loath to reapply because of the stress and the time involved:

It was completely degrading and humiliating, having to bare my soul to a government department. My first claim achieved lower care for life, which I felt then was correct. I delayed asking for a review for a long time, both because I did not want to interfere with a smoothly running life award and because I could not face the thoughts of being in that state for 6 months. . . . Now I have mobility difficulties but do not want to interfere with a smoothly running higher care. At a review I could be worse off with higher mobility and less care. The system penalizes you for coping. The money helps you but if you become well you lose it – and become very ill again through the stress of poverty . . .

One hundred and ninety-three respondents (31.8%), reported that their DLA award had been subject to a review. Of those who had experienced a review, 100 (51.8%) reported that the level of their award had stayed the same, 15 (7.8%) were reduced, and 13 (6.6%) stopped. Thirty-four respondents (17.6%) reported that the level of their award had been increased following review. When asked about the duration of their award following review, almost half (49.7%) reported that it had stayed the same, 4.1% reported that the time period had been reduced, and a similar number (4.7%) that it had been increased.

Although the above figures indicate that reviews resulted in a positive outcome slightly more often than reapplications this was by no means certain:

When my son reached twelve years the review was done . . . they only awarded middle rate care and low mobility. I appealed against this decision on the basis of his needs and was awarded the high rate on both.

A positive experience  There is a tendency when completing questionnaires of this nature for respondents to take advantage of having an opportunity to air grievances. Thus it is not surprising that the majority of comments received were negative – benefit recipients have few opportunities to have their voices heard and those who have experienced difficulties in applying for DLA may have been more likely to respond. Nevertheless, not all the comments were negative and attention should be drawn to those comments received from satisfied respondents:

Although it took a long time to complete the form . . . it seemed an OK experience, and of course I’m very pleased to have received DLA first time – it will benefit me greatly and I can get more help – acknowledgement of my disability.
Other positive comments related to the difference extra income makes to people’s lives:

Filling form initially off-putting and I delayed making claim for several months as a lot of questions not relevant . . . but once award made, money makes tremendous difference to life.

Discussion

The participants in this study were all recruited through voluntary agencies. Not all disabled people choose to contact voluntary organizations, and the makeup of respondents, for example the proportion who were aware of the eligibility criteria for DLA, and who had applied for this benefit, indicates that they were not necessarily typical of disabled people in Scotland. There were also differences between our participants and the population of disabled people in Scotland who are in receipt of DLA, in terms of both age, and nature of award.

There was a higher proportion of younger adults (<49) and a lower proportion of respondents post-retirement age amongst recipients of DLA in this study than in Scotland as a whole. A lower proportion of participants received both care and mobility components, 54% compared to 65% in Scotland as a whole. A higher proportion received care component only, 21% compared to 11%, and a lower proportion received mobility component only, 15% compared to 24% throughout Scotland. The significance of these differences would be difficult to establish; however, there are likely to be changes over time, and recent figures show that amongst new awards made during the year to February 2003 equivalent figures had shifted closer to those derived from participants in this study. Both care and mobility components were awarded to 60%, a reduction of 5%; care only to 21%, a rise of 10%; and mobility only to 18%, a reduction of 6%. Despite the possible limitations identified, the experiences of this self-selected sample are important in that no other study of this size has been carried out in Scotland, and few studies have provided such a large number of disabled people an opportunity to comment in this way.

Analysis indicated that more than 97% of the respondents who applied for DLA found the form difficult to complete. Forms were described as repetitive, confusing, lengthy and inappropriate. Appeals were commonplace and many applicants believed that decisions were inconsistent and often based on inadequate understanding of individual circumstances. Of respondents who had applied for DLA, 422 (80%) reported that they had had to seek assistance in completing their applications – thus an ‘industry’ has developed in order to service applications for DLA (and other benefits). Apart from the obvious stress and time commitment involved for applicants and their informal carers, the financial implications in terms of the amount of time that social workers, voluntary organizations, welfare rights officers and health professionals spend on providing this assistance must be considerable. Furthermore, access to advice
appears to be on an ad hoc basis rather than through official channels. Less than 5% of respondents had approached the Benefits Agency, the Benefits Enquiry Line, or a Citizen’s Advice Bureau for advice. These organizations are commonly assumed to be the ‘official’ sources of advice. While the majority of people who sought help with their applications were happy with the support received, our data indicate that applications which were subsequently awarded were often unsuccessful initially despite assistance having been sought. Furthermore, half the respondents who reported having contacted the Benefits Agency or the Benefits Enquiry Line were not satisfied with the service they received.

Although many of our findings are not new, the lack of commitment to address these issues and their implications appears to have received inadequate attention. Both the UK Government and the Scottish Parliament are committed to ‘transparency’. A system which neither the applicants themselves, nor the public sector workers whose role it is to support them can comprehend, is clearly at odds with their rhetoric.

Participants reported finding out about DLA through a variety of organizations or by chance. There was an ‘understanding’ that many applications would be turned down, possibly more than once. Applicants sought assistance in completing their forms from the same diverse range of agencies or informal supporters that had informed them of its existence. Applicants whose situation was unchanged lacked confidence that their award would not be altered when faced with a review or submitting a claim for renewal.

Our findings suggest that the apportionment of DLA is neither ‘open’ nor consistent. Lack of information, inequities in access to applications and quality of assistance when completing them, and rejection of claims which are subsequently awarded are a direct contradiction to the ethos of ‘supporting’ disabled people and the overall aim of social justice. In Scotland, where the incidence of long-term illness and disability is higher than elsewhere in the UK (Scottish Executive, 2000), access to disability-related benefits is vital in order to enable all individuals to participate in society. Although welfare benefits are a matter reserved to Westminster, the Scottish Parliament is responsible for implementing policy and as such should provide a clear pathway for disabled people to seek advice and guidance about welfare benefits. Many people who receive guidance relating to benefits do so as a by-product of their contact with social work departments, which regularly carry out benefit checks. However, many disabled people have no contact with social work. Information about disability-related benefits should be advertised regularly in local press and other media. Disabled people should be informed of eligibility criteria and supported in their applications for appropriate benefits. The Scottish Executive should also push for greater transparency in the way applications are dealt with. If applications are rejected, a full explanation should be sought. Applicants being assessed by an EMP or attending a tribunal should be offered support and provided with an advocate or interpreter as required. Poverty is all too commonly linked to
disability. In Scotland, where there are already marked and increasing inequalities between different localities, it is vital that lack of access to information and welfare benefits is not allowed to exacerbate the growing divide.

Conclusion

A move towards an inclusive society that enables individuals to participate fully requires that the breadline existence of many people living with a chronic disability must cease to be accepted as ‘the norm’. This would necessitate ensuring that benefits, and in particular ‘gateway’ benefits such as DLA, are easily accessible and are awarded in a consistent, equitable and transparent manner.

People need to know where to go to get advice and information on benefits and on the claims process. However, there is no directory of benefits information providers and the provision of advice is currently patchy. The Government publicizes new benefits and/or changes to benefits but it doesn’t regularly publicize the full range of benefits currently available. Both the Government in Westminster and the Scottish Executive should ensure that information about entitlements to benefits and support in making claims is available to people whether or not they are in contact with social work departments, giving the same prominence to DLA as it does to other benefits such as tax credits.

The Department of Work and Pensions needs to ensure that interpreting services are available to enable people to participate fully in the claims process.

Implications for Social Work Departments

Social workers are now found in a variety of settings including hospitals, community health partnerships, community schools and child development centres, and are involved in a range of interdisciplinary and interagency teams. They are thus ideally placed to address the lack of information, or misinformation, available to families affected by disability. However, despite contact with the above organizations and/or teams some individuals and families report that they have not been provided with information relating to welfare benefits (Banks and Pearson, 2003). Social workers should be proactive in disseminating information about benefits. As mentioned earlier, to qualify for DLA the need for help must exist for three months and be expected to last for a further six months. However, it is important that eligibility criteria are highlighted as soon as possible following the onset of a chronic condition or a traumatic event, as some families may lose contact with social workers, for example following discharge from hospital. Social workers should take advantage of their position and encourage other members of multi-disciplinary teams to broach the subject of welfare benefits with their clients and provide them with information relating to sources of further advice. Finally, applicants must have access to interpreters where required, and be supported at appeals. Social
work departments should ensure that the Scottish Executive and the Department of Work and Pensions are aware of any inequities in the benefit system.

Notes
1. Working Tax Credit and Child Tax Credit are allowances for people who have an illness or disability that puts them at a disadvantage in getting a job or have a severe disability.
2. Disability Agenda Scotland is an alliance of six of Scotland’s leading disability organizations: Capability Scotland, RNIB, RNID, Scottish Association for Mental Health and Sense Scotland. The sub-group Action on Benefits additionally included Glasgow Association for Mental Health and the National Deaf Children’s Society.

References
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