






Disabled people's costs of living

It is well known that disabled people face additional costs to enable them to meet their needs. However, there has been no clear evidence about the true extent of these costs. This research, conducted by the Centre for Research in Social Policy with the support of Disability Alliance, presents budget standards for groups of disabled people who have different needs arising from physical or sensory impairments. The budget standards represent the amounts disabled people (of working age) require in order to cover the costs of an acceptable and equitable quality of life. They were developed by disabled people themselves, through a series of rigorously conducted focus groups. The budgets were not based on 'wish lists'. Rather, they represent the minimum essential resources necessary to meet disabled people's needs, to enable them to achieve, as far as possible, a 'level playing field' with non-disabled people. They were arrived at through debate and negotiation within the focus groups. The research found that:

-  Disabled people experience additional costs in most areas of everyday life, from major expenditure on equipment essential for independence, to ongoing higher expenses for, for example, food, clothing, utilities and recreation.
-  The weekly budget standards required for disabled people are as follows:
 - £1,513 for a person with high-medium mobility and personal support needs;
 - £448 for a person with intermittent or fluctuating needs (i.e. from relatively negligible needs to higher needs);
 - £389 for a person with low-medium needs;
 - £1,336 for a person with needs arising from hearing impairment;
 - £632 for a person with needs arising from visual impairment.
-  Deaf people face particularly high costs due to their need for interpreter/communicator services.
-  The weekly income of disabled people who are solely dependent on benefits is approximately £200 below the amount required for them to ensure an acceptable, equitable quality of life.
-  Unmet weekly costs for disabled people who work 20 hours per week at the minimum wage are up to £189 (for those with high-medium needs).

Background

Disabled people have a disproportionate risk of being poor, i.e. of having an income below 60 per cent of the national median average. Department for Work and Pensions statistics for 2002–03 showed that 29 per cent of households with disabled people were poor, compared with 17 per cent of households without disabled people. However, these statistics underestimate the true extent of poverty among disabled people because they are based solely on income (including disability benefits), and do not take into account the additional costs disabled people may incur because of their disabilities.

Lack of information about disabled people's living costs mean that levels of nationally provided financial benefits and local services are determined using limited evidence. Certain state benefits are meant to offset, at least partially, the additional costs associated with disability, but the extent to which these benefits meet additional needs and costs is unknown.

The purpose of this study was to investigate the additional needs and associated financial costs of disability from the perspective of disabled people themselves. Rather than focusing on what disabled people *spend*, the research investigated what disabled people *need* in order to be on a 'level playing field' with non-disabled people. Participants were allocated to different groups, based on the type and degree of their disability, and they prepared in advance for group meetings. This ensured that the full extent of additional costs was explored.

The disabled person budget standards

The budget standards developed in the study are based on one disabled person living alone in suitably adapted, rented accommodation. They do not include prescription charges or any income, benefits, services or items provided by health, social or other services.

Most of the participant groups reported additional costs in most areas of expenditure examined, i.e. food, clothing, household maintenance, fuel and power, household goods and services, transport, communications, recreation/culture, education, health, personal care, insurance and special occasions. Those with the highest needs had the highest costs in all areas except:

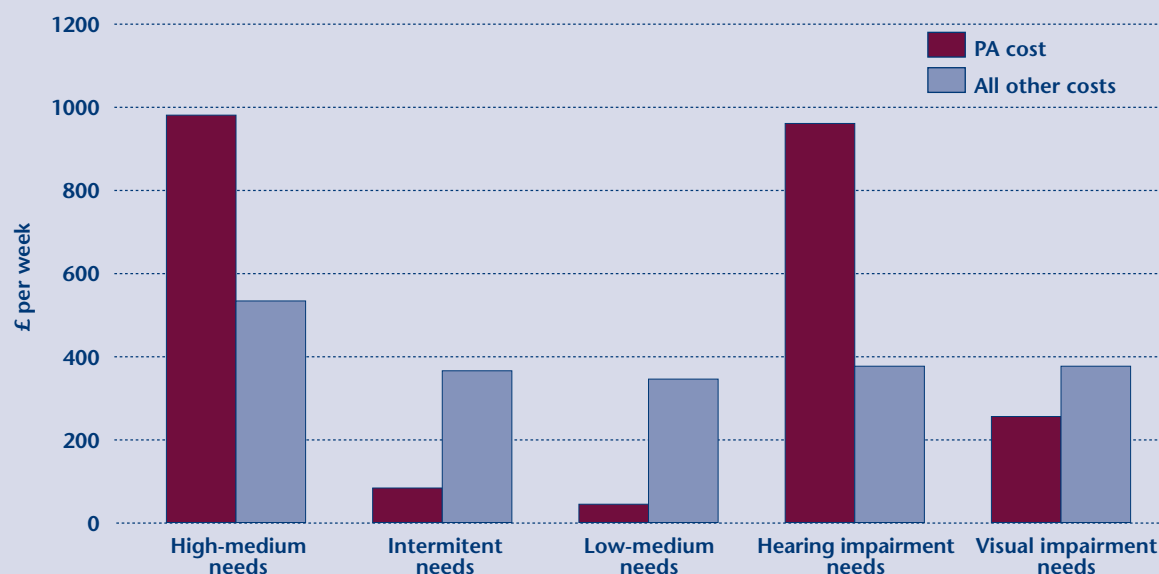
- transport – costs were highest for those with intermittent needs;
- communications and recreation/culture – costs were highest for deaf people.

Personal assistance costs

The biggest single cost for all groups was for personal assistance (see Figure 1). 'Personal assistance' was defined broadly to include interpreters for deaf people, trainers for visually impaired people, and personal care and other domiciliary services. Across all groups, the greatest need was for human assistance, rather than for adaptations and equipment.

The groups stated that someone with

Figure 1: **Personal assistance costs as part of disabled person budget standard totals**



Source: Disabled people's cost of living

high-medium needs would require constant personal assistance, including sleep-in cover. On top of wages for personal assistants (PAs), participants identified a number of additional indirect costs, including:

- PAs' costs when participating in activities;
- employers' liability insurance;
- laundering PAs' bed linen after sleep-in duties.

Consensus among the groups of deaf people was that for profoundly deaf people to have access to public, recreational and commercial services equal to those of hearing people, they would require extensive 'on demand' interpreter/communicator services. Current interpreter/communicator services are not designed to provide this level of assistance, which explains the very high costs in this area.

The groups of visually impaired people explained that specialist training was essential to support and enhance independence, but that current levels of training provision were inadequate. The groups therefore decided that the budget standard should allow sufficient resources to enable individuals to 'buy in' training as required, even if this had to be on a one-to-one (and thus not the most cost-effective) basis.

Benefits and the budget standards

The disabled person budget standard totals can be compared with maximum benefit levels, made up of Disability Living Allowance (DLA), Income Support and Incapacity Benefit, and taking into account Housing and Council Tax Benefits (see Table 1). To compensate (approximately) for the value of current social provision, these figures do not include PA costs.

Maximum benefit levels reflect disabled people's needs insofar as people with higher needs are eligible for higher benefit payments. The study finding that deaf people and people with visual impairments incur

similar costs is reflected in the similar benefit levels payable to both these groups of people.

However, even if receiving maximum benefits, disabled people still experience a substantial shortfall in income. The income of disabled people solely dependent on benefits, irrespective of the type or level of their need, is approximately £200 less than the weekly amount required for them to ensure a minimum standard of living. These figures suggest that, even without including PA costs, benefits meet only:

- 28 per cent of the costs of people with low-medium needs;
- 30 per cent of the costs of people with intermittent/fluctuating needs;
- 35 per cent of the costs of deaf people and people with visual impairments;
- 50 per cent of the costs of people with high-medium support needs.

This shortfall in income would need to be addressed through a combination of environmental improvements, enhanced service provision, improved benefits and/or wages from employment.

Paid work and the budget standards

The highest and lowest disabled person budget standards were compared with the wage of someone working 20 hours per week at the minimum wage, taking into account Working Tax Credit, Housing Benefit, Council Tax Benefit and DLA as appropriate. For disabled people on this minimum wage, unmet costs remain very high. Even if PA costs are excluded and it is assumed that full Housing and Council Tax Benefits are received, unmet costs would be between £118 and £189 per week (see Table 2).

To show how these figures vary according to the

Table 1: Maximum weekly benefits compared with disabled person budget standards (excluding PA and housing costs)

| | Maximum benefits payable per week (£) | Disabled person budget standard per week (£) | Unmet costs per week (£) |
|--------------------------------|---------------------------------------|--|--------------------------|
| High-medium needs | 235 | 467 | 232 |
| Intermittent/fluctuating needs | 90 | 298 | 208 |
| Low-medium needs | 79 | 279 | 200 |
| Hearing impairment needs | 110 | 310 | 200 |
| Visual impairment needs | 110 | 310 | 200 |

Source: Disabled people's costs of living

Table 2: Minimum wage model compared with disabled person budget standards (excluding PA and housing costs)

| | Total income per week (£) | Disabled person budget standard per week (£) | Unmet costs per week (£) |
|-------------------|---------------------------|--|--------------------------|
| High-medium needs | 278 | 467 | 189 |
| Low-medium needs | 161 | 279 | 118 |

Source: Disabled people's costs of living

Table 3: National average wage model compared with disabled person budget standards (excluding PA costs)

| | Total income per week (£) | Disabled person budget standard per week (£) | Unmet costs per week (£) |
|-------------------|---------------------------|--|--------------------------|
| High-medium needs | 451 | 533 | -82 |
| Low-medium needs | 351 | 345 | +6 |

Source: Disabled people's costs of living

range of disabled people's work situations, the highest and lowest disabled person budget standards totals are also compared with the national average full-time wage, plus DLA where appropriate (see Table 3).

People with low-medium needs need to receive the national average wage before their costs would be covered (and then only if there were no PA costs). However, for people with high-medium needs, an income consisting of the average wage and DLA would still not meet their needs. Even excluding PA costs, a person with high-medium needs in full-time work would face unmet costs of over £80 per week.

About the project

The study used needs-based consensual budget standard methodology. A total of 78 disabled people completed questionnaires and participated in a series of focus groups and workshops. Participants were recruited on the basis of their self-defined needs. Groups with common needs constructed budget standards for people in their circumstances (i.e. groups of participants with high-medium needs developed the budget standard for a person with high-medium needs, and so forth). All decisions about what should be included in the budget standards were made by

group members through a process of informed discussion, negotiation and 'check-back' groups. The fieldwork for the study took place in Derby, Birmingham and Nottingham in 2003-04.

How to get further information

The full report, **Disabled people's costs of living: 'More than you would think'** by Noel Smith, Sue Middleton, Kate Ashton-Brooks, Lynne Cox and Barbara Dobson with Lorna Reith, is published by the Joseph Rowntree Foundation (ISBN 1 85935 236 7, price £17.95).