

Department for Work and Pensions

Research Report No 542

Review of international evidence on the cost of disability

David Stapleton, Ali Protik and Christal Stone

A report of research carried out by Mathematica Policy Research, Inc. on behalf of the Department for Work and Pensions

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Contents

Acknowledgements	v
The Authors.....	vi
Abbreviations.....	vii
Summary	1
1 Introduction	3
2 Conceptual issues	7
2.1 The definition of disability.....	7
2.2 The definition of the extra cost of disability.....	9
3 Summary of evidence from the UK.....	13
4 Allowance and pilot programmes in the United States	15
4.1 Cash and counselling programme	15
4.1.1 <i>Overview</i>	15
4.1.2 <i>Early demonstration of cash and counselling</i>	17
4.1.3 <i>Process of determining programme allowances</i>	17
4.1.4 <i>Permitted use of allowance</i>	19
4.1.5 <i>Evaluation findings</i>	19
4.2 Supplemental Security Income for children with disabilities	20
4.2.1 <i>Overview</i>	20
4.2.2 <i>Cost of children with disabilities</i>	21
4.2.3 <i>SSI for children and extra cost of disability</i>	21

4.2.4	<i>Effect of SSI benefits for children on family income and parental behaviour</i>	22
4.3	Veterans' benefits	23
5	Evidence from other programmes and research	25
6	Conclusion	31
Appendix A	Summary of major United States disability programmes	35
Appendix B	Summary of disability allowance programmes from selected countries	39
References	49

List of tables

Table 1.1	Summary of research methods.....	4
Table 4.1	Key features of cash and counselling demonstration programmes, by state	18
Table 5.1	Disability-adjusted poverty standards for a family size of one	28
Table 5.2	Disability non-adjusted and adjusted poverty rates, by household types (percentages).....	29
Table A.1	Major United States programs for people with disabilities	36

List of figures

Figure 2.1	ICF conceptual model of disability.....	9
Figure 2.2	Illustration of the expenditure equivalence approach.....	12
Figure 5.1	Trends in estimated extra cost of disability in Ireland, 1995–2001	27

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Abbreviations

AA	Attendance Allowance
A&A	Aid and Attendance
ADA	Americans with Disabilities Act
ADLs	Activities of Daily Living
C&C	Cash and Counseling
DDA	Disability Discrimination Act
DLA	Disability Living Allowance
HBS	Household Budget Survey (Ireland)
HCBS	Home and Community-Based Services
HES	Household Expenditure Survey (Australia)
ICD-10	International Classification of Diseases, Tenth Edition
ICF	International Classification of Functioning, Disability and Health
PCS	Personal Care Services
SIPP	Survey of Income and Program Participation (U.S.)
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TANF	Temporary Assistance for Needy Families
VC	Veterans' Compensation

Summary

The Department for Work and Pensions (DWP) commissioned Mathematica Policy Research, Inc. (MPR) to conduct a review of the international literature on the extra costs of disability and determine how that literature could contribute to an assessment of two disability allowance programmes in the United Kingdom: Disability Living Allowance (DLA) and Attendance Allowance (AA). This is the final report for the study.

Allowance programmes are a conceptually appealing way to help people with disabilities and their families pay for goods and services that such individuals often need. The programmatic intent is to provide recipients with financial resources that they can use in a flexible and efficient manner to improve their standard of living, rather than providing specific goods and services. The Cash and Counseling (C&C) demonstration in the United States generated strong evidence of the advantages of allowance programmes. Demonstrations were conducted in three states, using low-income volunteers with disabilities who were randomly assigned to control groups (current programme) or treatment groups (experimental allowance programme). The allowance amount for each treatment subject reflected the cost of professional services that the individual was entitled to under the current programme. The allowances offered to treatment subjects in all three states measurably improved their lives relative to those of the control subjects. The demonstration programmes were somewhat more expensive than the existing programmes, but this is because administrative obstacles prevented many control subjects from receiving the services to which they were entitled.

Although we found studies comparing the performance of allowance programmes for people with disabilities relative to other types of financing schemes, our exhaustive search yielded very little information about how to objectively determine the size or adequacy of allowance payments. Many countries have allowance programmes for various groups of people with disabilities but we have not been able to find information on the rationale for specific allowance amounts. We surmise that most of these programmes initially set allowance rates based on some measure of reasonable expenses for relevant services; over time, adjustments are made to reflect inflation and political and fiscal realities.

The research literature also provides little practical guidance. Some of the literature is of little interest because it uses definitions of the extra costs of disability that are problematic for assessing allowance payments. Of the multiple definitions encountered, one stands out as the most appropriate in the context of allowance programmes: the 'expenditure equivalence' definition. Under this definition, the extra cost of disability is the amount of additional income a person with a disability would need to achieve the same standard of living as a similar person without a disability. 'Standard of living' in this context refers to an objective measure of individual or family well-being based on something other than income, such as measures of material hardship (for example, missing meals) or expenditures on goods and services not purchased to compensate for disability. An operational version of this definition provides a conceptually appropriate benchmark against which the adequacy of an allowance can be assessed.

In contrast, two other definitions from the literature would support benchmarks likely to be systematically too low or too high. Benchmarks based on the cost of extra goods and services used by the individual are likely to be too low because many people with disabilities face income constraints that lower their standard of living. Benchmarks based on the cost of extra goods and services required for the person to engage in the same activities as an otherwise comparable person are too high because they fail to recognise that, given any budget, the person can increase their standard of living by substituting inexpensive activities for expensive ones. For example, compared to a person with no disability, a person with a mobility impairment might be more likely to shop online rather than in stores because the cost of transportation for them would be relatively high.

Only a few studies have used the expenditure equivalence approach to measure the extra costs of disability in the United Kingdom, Ireland, the United States and Australia. All of these studies show that the extra costs of disability are very large when expressed as a share of household income. Unfortunately, none of these studies provide a sound basis for assessing the adequacy of the allowances provided by the AA and DLA programmes. The studies use operational measures of the standard of living likely to be unsuitable for these programmes. They are also based on more broadly defined disability populations than those targeted by AA and DLA and, with the exception of the UK study, they apply to people living in different economic and policy environments compared to AA and DLA participants.

Although the evidence from these studies is not immediately helpful, the studies do point toward research that could inform an assessment of AA and DLA. Some progress could possibly be made through a new analysis of the data used in the UK study. A more ambitious approach would rely on collecting comparable expenditure data from samples of AA and DLA households.

1 Introduction

Current disability allowance programmes in the United Kingdom have been strained by the sustained growth in the number of people obtaining benefits. Hence, these programmes – DLA and the AA – have come under increased scrutiny in recent years, and there is substantial interest in better understanding the rationale and impact of the programmes.

In this study, we address those issues by assessing whether there is any non-UK evidence about the extra costs that disabilities impose on individuals (other than reduced earnings capacity) and, if so, whether that literature could inform policy decisions in the United Kingdom about the appropriate size of disability allowances. MPR conducted an extensive literature search to identify conceptual and empirical methods for understanding how a disability affects a person's daily costs (Table 1.1).

This search turned up a small amount of literature that provides guidance on measuring these extra costs and their potential magnitude. First, we identified several programmes in the United States that provide allowances to individuals with disabilities to cover the extra cost of impairment, excluding programmes designed solely to replace lost earned income. One of them was Cash and Counselling (C&C), a consumer-directed care model in which individuals with disabilities are given cash allowances to hire carers and buy care-related equipment. We also studied the Supplemental Security Income (SSI) programme for children with disabilities. Although SSI for adults is an income-replacement programme, for children it can be seen as an allowance for the extra time and resources that parents must spend to raise a child with a significant disability. In addition, we reviewed the Veterans' Aid and Allowance programme, which provides allowances to veterans with service-related disabilities. Second, we identified allowance programmes in a number of European countries similar to those in the United Kingdom. However, we did not find detailed documentation on how these programmes determined the amount of allowances or how successfully they addressed extra costs. Third, we identified a few research studies that applied a conceptually sound approach to measuring the extra cost of disability using available survey data.

Table 1.1 Summary of research methods

<p>Search engines and databases</p> <ul style="list-style-type: none"> • SocINDEX with Full Text • EconLit • Academic Search Premier • MEDLINE • ProquestDirect • Journals@Ovid • National Rehabilitation Information Center's REHABDATA • Google <p>Miscellaneous sources</p> <ul style="list-style-type: none"> • Reference sections of relevant articles • MPR project and report archives <p>Government and organisational archives</p> <ul style="list-style-type: none"> • Kaiser Family Foundation • Centers for Medicare & Medicaid Services (CMS) • U.S. Department of Health and Human Services (HHS), Office of Disability, Aging, and Long-Term Care Policy • U.S. Department of Veterans Affairs, Veterans Benefits Administration • HHS, Social Security Administration • Organisation of Economic Co-operation and Development • European Commission's Mutual Information System on Social Protection • Programmatic websites of developed countries <p>Targeted material</p> <ul style="list-style-type: none"> • Allowance programmes* • Rigorous impact evaluations of allowance programmes** • Empirical research on extra costs of disability***

* Initially, we sought descriptions of disability allowance programmes. After identifying them, we sought information on the conceptual and operational bases for allowance amounts.

** Numerous evaluations of C&C programmes have been conducted but only the four experimental evaluations conducted by MPR produced methodologically rigorous estimates of impacts.

***Research studies that examined the extra costs associated with disabilities were identified using search terms such as 'costs of disability', 'extra costs,' 'additional costs,' 'economic costs,' 'personal assistance costs,' and 'cost of living and disability.' We reviewed studies to determine whether the researchers examined the extra costs, and excluded articles that focused on income replacement due to reduced labour force activity (except in the instance of carers). We also excluded studies that were theoretical rather than empirical.

While the motivations behind each programme vary and are different from those of the UK programmes, we think the international information will be useful in assessing DLA and AA.

To conduct such an assessment, it is necessary to define the extra costs of disability in a conceptually meaningful way. In Chapter 2, we discuss conceptual issues regarding the extra costs of disability and how best to define them. While several approaches have been used, we argue that the 'expenditure equivalence' or 'standard of living' approach is the most appropriate for purposes of informing allowance programmes. The basic idea behind this approach is that individuals with disabilities typically cannot attain as high a standard of living with a given level of income as those without disabilities who are otherwise similar. 'Standard of living' in this context must be defined independently of income. In other words, a person with a disability must spend more, to achieve a given standard of living than a comparable person without a disability. The additional spending required is the extra cost of disability.

This measure of the extra cost of disability is pertinent to allowance programmes because it represents the size of an allowance that, given other income, would allow the person with a disability to achieve the same standard of living as the otherwise comparable person.

Application of this approach has been limited because of the scarcity of standard-of-living measures that are independent of income; most of these measures are based on income, with adjustments for various factors such as household size and composition – but not for disability. In some of the empirical studies that use the expenditure equivalence approach, researchers have employed various measures of hardship experienced by households as an empirical proxy for standard of living. The idea is to find the allowance that would have to be provided to a person with a disability (or a household containing such a person) so that the individual would experience hardship no more frequently than an otherwise comparable person (Zaidi and Burchardt 2005; Saunders 2006; She and Livermore 2007).

What constitutes hardship is, of course, highly subjective, and measurement of hardship is problematic. Further, using a hardship measure to inform the size of an allowance suggests a very specific programmatic goal: prevention of hardship. Nonetheless, we think that this approach is the most conceptually compelling way to measure the extra cost of disability, especially to inform the size of allowances. We recommend that future efforts to generate information on the extra cost of disability follow this conceptual approach; studies that define 'standard of living' in a manner consistent with the stated goals of allowance programmes would be especially helpful. In Chapter 6, we identify some available opportunities to generate such information, although these too are limited by the measurement of standard of living.

Because a primary goal of this study is to assess whether international literature exists and could inform policy in the United Kingdom, we introduce this report by describing our method for identifying relevant articles. The findings from our search are presented as follows. In Chapter 2, we discuss the conceptual issues inherent in measuring extra costs of disability. In Chapter 3, we summarise the UK allowance programmes, DLA and AA, along with the findings from an earlier review of UK studies. In Chapter 4, we describe U.S. allowance programmes and in Chapter 5, we present evidence from other programmes as well as results from empirical studies based on the expenditure equivalence approach. We conclude our report in Chapter 6. A summary of major U.S. programmes targeting individuals with disabilities and descriptions of allowance programmes in other countries appear in Appendices A and B, respectively.

2 Conceptual issues

2.1 The definition of disability

Before defining its extra costs, we first develop consistent conceptual definitions of disability and the factors that determine it. Unlike age and gender, which are readily identifiable individual attributes, disability is a complex interaction between a person's health condition and the social and physical environment and hence has been defined in a variety of ways.

The two most common conceptual models of disability used in the United States are the World Health Organization's (WHO 2001) International Classification of Functioning, Disability and Health (ICF), and a very similar disability model developed by Saad Nagi (1965, 1976). Both models are 'social' or 'medical-environmental' models, because they explicitly recognise disability as a dynamic process involving the interaction of a person's health condition with other personal characteristics, and with the physical and social environments. These models have replaced the 'medical model', which posited that health conditions alone are the cause of disability.

Under the ICF and Nagi models, changes in non-medical personal characteristics, the physical environment or the social environment can impact a person's ability to function and participate in activities, holding the person's health as a constant. Jette and Badley (2000) provide a detailed description and comparison of these models. In this report, we adopt ICF concepts to create operational definitions of disability. The concepts used are: **impairment**, **activity limitation** and **participation restriction** (see WHO 2001). A prerequisite for each of these concepts is the presence of a health condition. Examples of health conditions are listed in the International Classification of Diseases, Tenth Edition (ICD-10), and they encompass diseases, injuries, health disorders and other health-related conditions.

An **impairment** is defined as a 'significant' deviation or loss in body function or structure. For example, a loss of a limb or vision may be classified as impairments. There are broadly three types of impairments: sensory impairments, which primarily include difficulty hearing or seeing; physical impairments, which include difficulty with moving, climbing, reaching and other body functions; and mental impairments, which include difficulties in learning, remembering, concentrating, or performing other mental functions.

An **activity limitation** is defined as a difficulty an individual may have in executing common daily activities. For example, a person who experiences difficulty in dressing, bathing, toileting or performing other such daily activities may be classified as having an activity limitation. Questions concerning the difficulties with activities of daily living (ADLs) often appear in surveys.

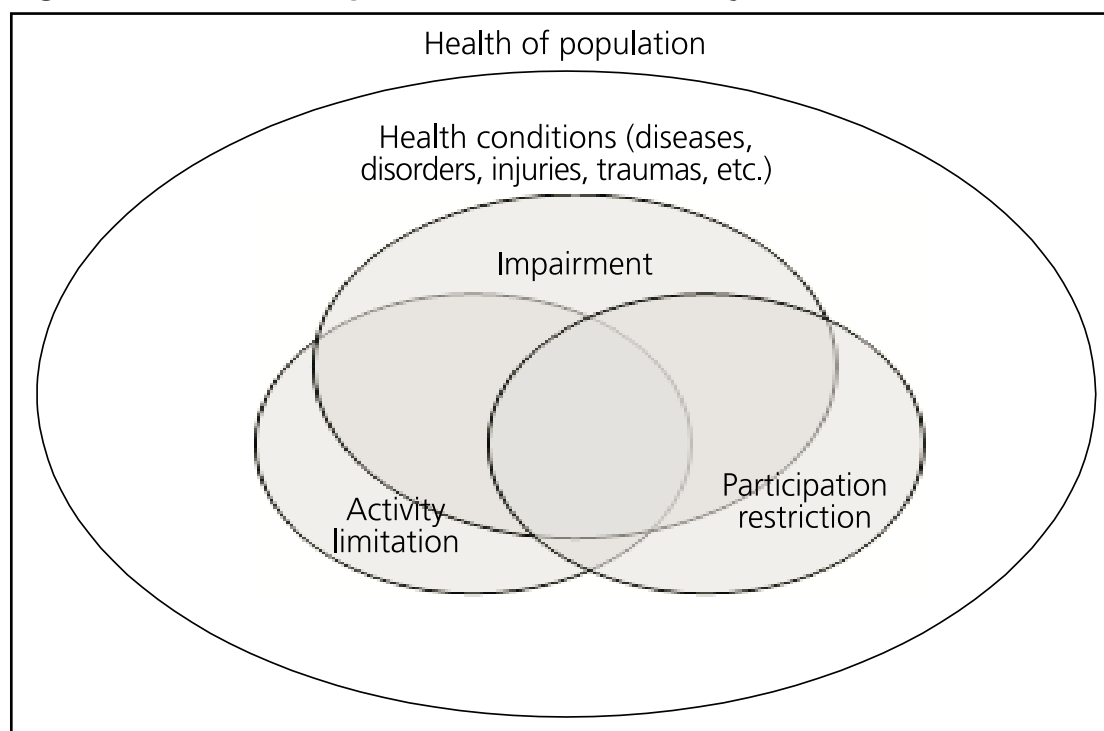
A **participation restriction** is defined as an inability to fully engage in a major age-appropriate social activity. For example, a working-age person with a severe health condition may have difficulty in participating in employment, at least in the absence of a supportive environment – one that is accessible and logistically supportive. In some surveys, participation restrictions are identified by questions that ask whether the person has a long-lasting health condition that limits their ability to work, or whether a health condition affects his or her ability to go outside the home to go shopping, to church, or to the doctor's office. These questions do not explicitly recognise the potential role of the environment. Hence, one person might answer 'yes' to such a question, even though another person with exactly the same condition might say 'no' because of a more favourable environment.

In the context of these concepts, a disability can be defined as the presence of a health-based impairment, an activity limitation, or a participation restriction. This concept is similar to the definition used in the Disability Discrimination Act (DDA). According to the DDA, 'a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.'

While these concepts may seem to follow a progression – that is, an impairment leading to an activity limitation, leading to a participation restriction – this need not be so. A person may have a participation restriction that is the direct result of the social environment, without an activity limitation or impairment. For example, someone diagnosed as HIV positive with no impairment or activity limitation may be refused employment unlawfully based on their health condition. Similarly, people with a history of mental illness, but no current loss in capacity or activity limitation, may also be unlawfully refused employment based on their past history. Figure 2.1 provides a summary of these ICF concepts. It shows that, while these concepts overlap, they are not nested. The ICF universe is the health of the entire population. The shaded areas in Figure 2.1 contain the population with disabilities, based on ICF concepts.

As Burchardt (2004, p. 736) recognises, the social model of disability fits within the broader conceptual framework of the 'capabilities approach,' which originally was proposed by Sen (1980) as an approach for understanding why many individuals have very low standards of living.¹ In the capabilities approach, it is not just the individual's characteristics that matter; the economic, social, and physical environments also matter. A social, economic, or physical barrier can make any individual, no matter what his or her characteristics, 'capability poor.' Broadly speaking, the differences between the social model of disability and the capabilities approach are philosophical.

Figure 2.1 ICF conceptual model of disability



2.2 The definition of the extra cost of disability

There is little disagreement with the idea that disability imposes extra costs on individuals and their households, above and beyond the often negative effect on the individual's earnings. There is also, however, little agreement on the definition of 'extra cost of disability', as is apparent from Tibble's (2005) review of the extra cost literature in the United Kingdom. We identify three conceptually distinct approaches:

¹ Sen (1980) did not propose the 'capabilities approach' for people with disabilities, per se. However, his propositions are broad enough to apply to any groups that are disadvantaged. Nussbaum (2002) also tried to formalise the approach in the context of disadvantaged women but again, the formalisation is applicable for people with disabilities as a disadvantaged group.

- The 'goods and services used' approach estimates the cost of extra goods (for example, powered scooter) and services (for example, taxi rides) that an individual with an impairment (for example, mobility) actually uses in the performance of certain activities (for example, travel outside the home in a reference period). Measurement under this definition is relatively easy in principle; it is only necessary to observe how much people with disabilities spend on services to support an activity, and compare it to that spent to support the same activities by otherwise comparable individuals without disabilities. In practice, it is easier to estimate cost using this approach for goods and services used exclusively by individuals with disabilities (for example wheelchairs), than for goods and services that are also used by individuals without disabilities, but to a different extent (for example, home cleaning and maintenance services). The 'goods and services used approach' is similar to the 'comparative approach,' described in Tibble, that compares spending patterns between people with disabilities and similar groups without disabilities. The obvious limitation of this approach is that people with disabilities engage in the activities less often than those without disabilities, because of the extra cost, assuming income to be constant. Hence, extra cost, defined in this manner, is lower than it would be if the individual with disabilities engaged in the activity at the same level as others. In the extreme, extra costs for an activity defined in this manner could be negative, if people with disabilities rarely engage in the activity because it is so expensive.
- The 'goods and services required' approach estimates the cost of extra goods (for example, powered scooter) and services (for example, taxi rides) that an individual with an impairment (for example, mobility) would need to perform a specified set of activities in which the person currently may not be engaged (for example, commute to work). In Tibble, this approach is labelled as the 'subjective approach.' It is more difficult to obtain information on this concept of extra cost than the cost of goods and services used, because it requires people to speculate about the extra costs of doing things that they actually do not do, or do only in a limited way (for example, telecommute instead of physically commute). Extra costs for goods and services required are likely to be higher than extra costs for goods and services used, because the latter likely reflect substitute activities.
- The 'expenditure equivalence' approach estimates the difference between the costs that a person with a disability would need to incur to attain some objective, compared to an otherwise similar person without a disability who has the same objective. The ultimate economic version is the answer to the question: *How much extra money would a person with a disability need to spend on all activities*

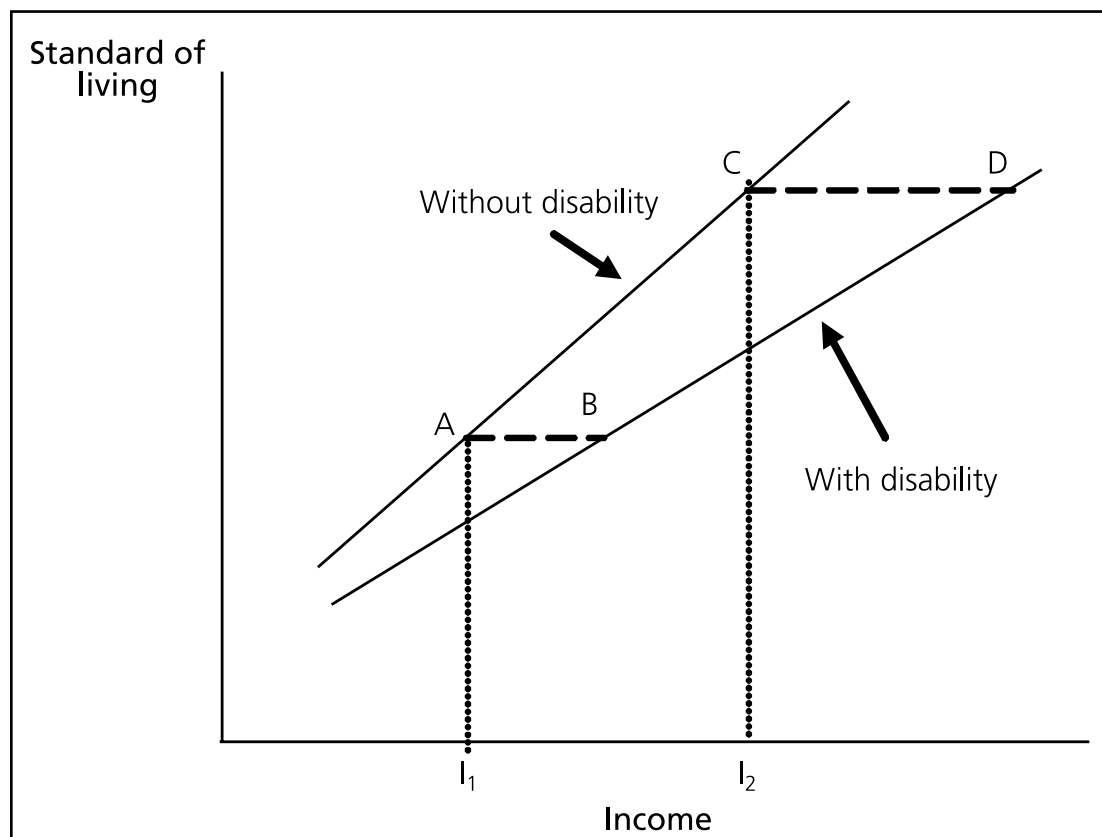
*to achieve the same level of utility he or she could achieve with no disability.*² More practical versions of this approach would consider expenditures for a less abstract objective, such as the achievement of some indicator of standard of living that is not based on income. The basic idea behind this approach is that individuals with disabilities typically cannot attain as high a standard of living with a given level of income as those without disabilities who are otherwise similar. Conversely, a person with disabilities must spend more to achieve a given standard of living than an otherwise comparable person. The additional expenditure required is the 'extra cost of disability' (Zaidi and Burchardt 2005; Saunders 2006).

We find the expenditure equivalence definition to be the most appealing approach conceptually, given the intent of allowance programmes. Hence, we examine this definition in greater detail. It is illustrated in Figure 2.2, which shows hypothetical relationships between income and an objective measure of standard of living for two individuals, differing only in that one has a disability and the other does not.³ At any level of income, the individual without the disability attains a higher standard of living because it is more expensive for the individual with a disability to attain any standard of living. The difference in standard of living widens as the income increases, on the assumption that the marginal cost of increases in standard of living are higher for the person with the disability.

² Sen (1980) argued and Burchardt (2004) restated that income is likely to be a poor proxy of utility. Different individuals convert income into utility at different rates. Moreover, different individuals can have different levels of utility with the same level of income or the same individual may obtain different levels of utility with the same income at different points in time (Burchardt, 2004). This latter process is sometimes referred to as 'adaptive preferences'. The expenditure equivalence approach, however, assumes that if the cost of disability is compensated for, individuals with disabilities would achieve the same level of utility as individuals without disabilities at the same level of income (apart from the compensation).

³ We have assumed that the relationship between income and standard of living is linear for ease of explanation. Whether the relationship is linear or not is an empirical question that can be tested.

Figure 2.2 Illustration of the expenditure equivalence approach



If income is equal to I_1 , the extra cost of disability is the horizontal distance between points A and B: that is, the amount of additional income the person with a disability would need to achieve the same standard of living as a person without a disability having an income of I_1 . The extra cost of disability is larger at higher income levels; for instance, at I_2 it is equal to the horizontal distance from C to D. This follows from the assumption that the marginal cost of increasing the standard of living is higher for the person with a disability.

The expenditure equivalence definition of extra cost is consistent with our understanding of the intent of allowance programmes: to help the recipient attain a standard of living, however defined, that is closer to the standard they would achieve under the counterfactual of no disability. An allowance exactly equal to the extra cost of disability under the expenditure equivalence definition would, as defined, be just enough for the individual to attain the counterfactual standard.

If the individual bears the full cost of extra goods and services used because of a disability, then their 'cost of goods and services used' will be too low as a measure of the allowance needed to attain the same standard of living as the individual without a disability, because they would have cut back on actual activities to stay within a given budget constraint. Conversely, the extra cost required for the person with a disability to engage in the same activities as the person without a disability would be greater than the allowance needed for them to attain the same standard as the person without a disability, because the individual with a disability could substitute less expensive for more expensive activities to attain a higher standard of living.

3 Summary of evidence from the UK

DLA was introduced in Great Britain/UK in 1992 to address the extra costs associated with physical and mental disabilities. Specifically, it provides a cash benefit for individuals who need significant help with personal care and/or mobility. Eligibility is not based on income or work history but rather, on the extent of care and mobility needs, the time-span of the disability (more than six months), certain residency requirements and age (under 65 at the time of claiming). DLA is made for either a fixed or indefinite period. The care component has three levels of award and the mobility component has two, depending on extent of assistance needed. Although the benefit is designed to assist those who require extra help with personal care and mobility, receipt of paid assistance is not required to get the benefit.

AA is similar to DLA but is intended for individuals 65 and older. Its eligibility, application, approval and payment rules are similar to those of DLA. Receipt of the benefit is not based on work history and usually is not affected by savings or income. AA differs from DLA in its rate scheme. AA has a single benefit component, compared to DLA's two. The single component establishes the level of needed assistance and the corresponding payment. Level of need is based on the need for help or supervision either during the day or night, or throughout both, which determines eligibility for one of two payment rates. In addition, receipt of either DLA or AA may increase the level of benefits or credits from other social welfare programmes, such as Housing Benefit, Council Tax Benefit, Working Tax Credit or Pension Credit.

Tibble (2005) reviewed United Kingdom studies that estimated the extra costs of disabilities. This review examined six studies, organised into four categories based on the conceptual definition of extra cost:

- **Subjective.** These studies essentially used the goods and services required definition.
- **Comparative.** These studies essentially used the goods and services used definition.

- **Standard of living.** The one study in this area used the expenditure equivalence definition.
- **Budget standard.** These studies used focus groups to identify lists of required disability-related items but did not quantify expenditures.

The six selected studies agreed that there were higher costs or different spending patterns for individuals with disabilities, compared to those without. The studies did not agree on the amount of the overall extra costs. Estimates ranged from £7.24 to £1,513 per week. Tibble attributes the wide range to differences in study design, conceptual definitions of extra costs and population characteristics.

The review by Tibble found a variety of factors that influence the size of extra costs. Several studies found that type of activity limitation has at least a minor effect on the amount of extra costs; higher costs are associated with locomotion, eating, drinking and personal care limitations. Severity of an activity limitation or impairment might be more important than type. Martin and White (1988) conclude that extra costs also depend on income as well as geographic location, which impacts on price and availability of goods and service.

Zaidi and Burchardt (2005) merits additional attention as the one study reviewed by Tibble that used the expenditure equivalence approach.⁴ The authors use data from the 1996-97 *British Family Resources Survey*, and the 1999-2000 wave of the *British Household Panel Survey*. Both of these include questions on disability, its severity and on restrictions of social and economic activities. The authors define a composite measure of standard of living based on a basket of non-disability-related highly discretionary goods (mostly consumer electronics) and compare individuals with and without disabilities at the same level of income. They provide estimates for extra income necessary for people with disabilities at the same level of income to achieve the same standard of living – which is, by definition, the extra cost of disability according to this approach. The extra cost estimates provided are thus, sensitive to the items included to define standard of living. However, the authors report that changes in the items do not alter the outcomes significantly. The extra cost of disability calculated by Zaidi and Burchardt (2005) for non-pensioner households⁵ ranges from £173 for individuals to £412 for couples who both have disabilities. For pensioner households, estimates range from £124 for individuals to £281 for couples who both have disabilities. This study does not include households with children (due to lack of disability information) or households with sizes larger than two.

⁴ Berthoud *et al.* (1993) was the first to use the expenditure equivalence approach, using data from a 1985 UK household survey. Zaidi and Burchardt build on Berthoud and his colleagues' study using more recent data.

⁵ Non-pensioner households are those in which at least one member works.

4 Allowance and pilot programmes in the United States

4.1 Cash and counselling programme

4.1.1 Overview

C&C is a consumer-directed care model that has been implemented in some U.S. states to provide allowances for personal care services. This section draws heavily on Brown *et al.* (2007). The intent of the programme is to provide consumers with greater control over the care they receive. C&C gives consumers a monthly allowance that they may use to hire carers, who in certain cases are family members, and to purchase care-related goods and services. Consumers can also get help to manage their care plans and budgets from representatives known as 'fiscal intermediaries'. The programme also provides counselling on monetary matters and service access.

Historically, the federal-state Medicaid programme has financed personal care services (PCS) or Home and Community-Based Services (HCBS) for individuals who have sufficiently severe disabilities and sufficiently low income and resources to

qualify.⁶ Medicaid would purchase the services directly, on behalf of the individual, from Medicaid-certified home care agencies on a fee-for-service basis. Although this payment was sizeable, agency-based services failed to reflect consumers' preferences for the amount and type of services they required, or the timing, method, and the choice of agency delivering these services, and did not respond to consumer interest in engaging non-agency carers. The federal government has encouraged states to implement C&C programmes, both to give consumers more control over the care they receive, and to encourage them to use this care more efficiently. The first C&C demonstration programme started in 1998 in Arkansas. Currently, 12 states have C&C programmes.

C&C is similar to DLA and AA, the two UK-based allowance programmes, in that they all make contributions towards covering extra costs of disability, especially personal assistance services, in some form. One significant difference is that the allowance under C&C is large enough to cover the cost of a particular type of care, personal assistance, for people with relatively low family incomes, while DLA and AA are not intended to cover the full costs of care and are not targeted exclusively at those with relatively low incomes. The local social services authority in the UK usually provides a carer if a person with a disability needs one, and the individual is expected to make a contribution that is income dependent. DLA/AA is usually taken into account to calculate the contribution of the individual, but it regularly falls short of the total cost. Hence, the allowance under C&C essentially covers the cost of services that in the UK might be covered by a combination of contributions from the local social services authority and DLA/AA.

Despite these differences, the C&C experience is informative to an assessment of DLA and AA because it provides information on the consequences of providing allowances intended to address the extra cost of disability.

⁶ Appendix A provides a summary of major United States programmes for people with disabilities. Medicaid is a health insurance programme for low-income individuals and families, although other characteristics including age, disability, resources and U.S. citizenship or immigration status are also used to determine eligibility. It is jointly funded by the states and federal government, and is managed by the states. PCS (see Appendix A) is a Medicaid programme which pays for individual assistance in everyday activities for the elderly and people with disabilities. It does not, however, include medical care. HCBS is a Medicaid programme which pays for a wide range of services and products to allow people with disabilities to live in the community rather than institutional settings. Programmes vary by state and individual need and may include home nursing and provision of medical equipment as well as counselling and assistance with everyday activities.

4.1.2 Early demonstration of cash and counselling

MPR evaluated five-year demonstrations of C&C programmes in three states – Arkansas, Florida and New Jersey. In the following sections we describe those targeted in these three states, how the allowances were calculated, permitted uses of allowances, and findings from the demonstration’s evaluation. The evaluation used an experimental design to produce unbiased estimates of programme effects, and sample sizes were adequate to detect programme effects of policy-relevant magnitude. Table 4.1 presents a summary of key features of the C&C programme in each of the three demonstration states.

The three states offered different versions of the programme while adhering to the basic tenets – flexible allowance, provision for use of representatives to make decisions regarding care management, limited restrictions on the choice of carer, and availability of counselling and fiscal services. Arkansas and New Jersey offered the programme to adults (18 and over) with physical disabilities. Florida offered it to children and adults with developmental disabilities, frail older adults (over 60) and non-elderly adults with physical disabilities. Arkansas and New Jersey provided consumers who were eligible for their Medicaid PCS benefits, but had not necessarily enrolled, with allowances that covered services such as help with eating, bathing, housekeeping and shopping. Florida offered allowances to individuals who already were receiving HCBS services, such as in-home nursing, professional therapies, care-related supplies and equipment and PCS.

4.1.3 Process of determining programme allowances

Calculations of programme allowances also varied by state. In Arkansas and New Jersey, the number of hours in consumers’ Medicaid PCS plans was multiplied by an hourly rate to determine cash allowance. This rate was set below the average rates paid to agencies under the agency-based model and the difference was used to pay for counselling services and the fiscal intermediaries in the demonstration programmes. Plan hours also were restricted to a maximum of 16 per week in Arkansas and 25 per week in New Jersey, unless there was special authorisation for additional hours for activities of daily living.

Table 4.1 Key features of cash and counselling demonstration programmes, by state

Feature	Arkansas	Florida	New Jersey
Eligible population	Adults (elderly and non-elderly) with physical disabilities (may also have cognitive disabilities) who were eligible for Medicaid PCS programme	Elderly and non-elderly adults with physical disabilities, and children and adults with developmental disabilities who were receiving services under the HCBS waiver	Adults (elderly and non-elderly) with physical disabilities (and perhaps cognitive disabilities) who were already enrolled in the state's Medicaid personal care programme
Services included in calculating the allowance amount	Personal care with activities of daily living, such as eating, bathing, dressing, toileting, and transfer, and with instrumental activities such as housework and meal preparation	HCBS waiver services, except case management/support coordination*	Personal care with activities of daily living
Hiring restrictions	Could not hire legally responsible relatives (such as spouses or parents) or representative	None	Could not hire representative
Maximum plan hours	16/week	None	2.5/week
Median monthly prospective allowance of all demonstration enrollees	\$313	\$829 (adults) and \$831 (children)	\$1,097
Participation in other consumer-directed or home care programmes	Demonstration enrollees could also participate in the HCBS waiver programmes	For adults with developmental disabilities, the demonstration excluded some northern counties with a state-funded consumer-directed programme	Demonstration enrollees could not participate in HCBS waiver programmes or a state-funded consumer-driven programme

Source: Brown *et al.* (2007)

*HCBS services covered under Florida's waiver included a wide variety of services, including behavioural therapy and personal care supplies, as well as personal care.

In Florida, the cash allowance was based on the consumer's historical experience under Medicaid and their current Medicaid care plan.

To keep expected programme costs comparable to what they would have been under agency-based care, Arkansas and Florida applied adjustment factors to consumers' allowances. Both states had determined that, during the pre-demonstration period, recipients of covered services had not, on average, received all of the services in their plans (for example, because in-home services were suspended during hospitalisations). In contrast, New Jersey determined that consumers' actual and planned costs had been roughly equal historically, indicating that adjustment factors were not necessary to keep costs comparable to anticipated costs for agency care. Median monthly allowances calculated for adult demonstration participants varied considerably by state, ranging from \$313 in Arkansas, to \$829 in Florida and \$1,097 in New Jersey. The median for Florida children was \$831.

4.1.4 Permitted use of allowance

Consumers under all three demonstration programmes were only allowed to use their allowances on goods and services related to their disability. However, the list of allowable purchases was broad enough to include purchases of transportation services, laundry services, insurance and kitchen appliances, for example. Consumers could also choose to receive about 10 to 20 per cent of their allowances in cash to cover incidental expenses. There were also provisions for saving parts of their allowances for future one-time, substantial purchases such as home modifications.

4.1.5 Evaluation findings

MPR conducted an impact evaluation of the C&C demonstrations in Arkansas, New Jersey and Florida using an experimental design, as mentioned above. After a baseline interview of a random sample of Medicaid participants, individuals were randomly assigned either to a treatment group, whose members were offered a monthly allowance, or to a control group, whose members had to obtain their PCS through the traditional agency-based model. Programme effects were measured by comparing the post-enrolment outcomes for the full treatment and control groups, regardless of whether a particular treatment group member actually received the monthly allowance.

- Effect on use and well-being
 - The treatment group was significantly more likely to receive paid personal assistance, compared to the control group. However, on average, treatment group members received less unpaid care than control group members, resulting in slightly, to moderately, lower total hours of care for elderly and non-elderly adults in all states and for children in Florida.
 - Treatment group members were much more likely than control group members to have their needs met and to be very satisfied with their care.

- There is some evidence of reductions in the number of adverse care-related events and no evidence of increases.
- More than half of the participants reported that the programme had improved their lives a great deal.
- Effect on cost of Medicaid
 - Medicaid personal care costs were significantly and substantially higher for the treatment group than for the control group in every state and age group. One important reason for this result is that many control group consumers did not receive the paid services authorised.
 - Other Medicaid costs were lower for the treatment group but by modest amounts (for example, lower use of long-term care services, including nursing homes and home health care).
 - Total Medicaid costs were higher for the treatment group in every state and age group, but not significantly so in most cases.
- Effect on paid and unpaid carers
 - Treatment group carers for adults provided fewer total hours of care than control group carers in Arkansas and Florida but more hours in New Jersey.
 - More than two-thirds of the workers hired directly by treatment group members were previously unpaid carers – mostly family members.
 - Treatment group carers were much more satisfied with the care that consumers received and they worried less about them.

The C&C demonstration does not provide information on the extent to which the allowances were sufficient to fully compensate participants for the extra cost of disability. The allowance amounts were based on care plans.

4.2 Supplemental Security Income for children with disabilities

4.2.1 Overview

SSI is the U.S. federal programme that provides benefits to low-income individuals who either have disabilities (including children) or are at least age 65 with a cash benefit; in 2007, the allowed benefit was up to \$623 for an individual. Some states provide a supplement to the federal amount, and most make SSI recipients automatically eligible for Medicaid, as well as other government services. SSI was not designed as an allowance programme to compensate for the extra cost of disability but the benefit for children with disabilities, in essence, functions as such a programme for their parents.

In general, children with significant chronic conditions or mental or physical impairments pose financial burdens on their families beyond those that might be covered by health insurance. For many, the largest burden is the cost of the extra time

that parents spend caring for the child – time that, otherwise, might be devoted to paid work or other productive activities. Other important burdens include trained childcare providers, respite care, special shoes and clothing, diapers, specialised toys and educational equipment, tools to facilitate communication, modifications to the home or specialised equipment, alternative foods, transportation, training for parents and uncovered medical costs.

The amount of SSI payments for a child depends on the family's other income. Over the years the Social Security Administration (SSA) has developed a complicated set of rules to determine both total family income and the amount of that income deemed available to support the child. The deeming rules make allowances for income needed to support other family members. The amount deemed available for the child is subtracted from the maximum allowable to determine the amount of the benefit.

Before 1991, relatively few children received SSI benefits, in large part because there was no child equivalent to SSA's residual functional assessments to determine whether an adult could work. A 1990 Supreme Court ruling in the *Zebley* case led to a large expansion. The *Zebley* ruling required SSA to promulgate rules for an analogous assessment, to determine if the child could participate fully in education and other major childhood activities.

4.2.2 Cost of children with disabilities

A number of studies report the negative impacts of the presence of children with disabilities on parental employment (Kuhlthau and Perrin 2001; Heck and Makuc 2000; Lukemeyer *et al.* 2000). Based on a sample of welfare recipient families in four counties in California, Lukemeyer *et al.* found that only 29 per cent of mothers caring for disabled or chronically ill children and 19 per cent of mothers caring for severely affected children were employed, compared to 39 per cent of mothers of healthy children. Accounting for the reduction in the probability of employment and in the hours worked for mothers of severely impaired children, the authors calculated an average loss of approximately \$80 in mothers' income per month. This calculation was based on a minimum hourly wage rate of \$5.15 at that time, and presumably would be higher for higher-income parents. Kuhlthau and Perrin also report lower probability of employment for fathers of children with different types of limitations, compared to fathers of healthy children. The children with disabilities in these studies were not necessarily on SSI and the disabilities of many of them might not have been severe enough for them to qualify.

4.2.3 SSI for children and extra cost of disability

The purpose of SSI for children is to support and preserve the capacity of families to care for their disabled children in their own homes by meeting some of the additional disability-related costs; compensate for some of the income lost because of the everyday necessities of caring for a disabled child; and meet the child's basic needs for food, clothing and shelter. This rationale for providing support to children with disabilities to offset the disparities between them and other families with children is, to some extent, a version of the 'expenditure equivalence' approach to extra cost.

4.2.4 Effect of SSI benefits for children on family income and parental behaviour

Very little research has been conducted on the effects of SSI for children. Two studies have examined the effect of SSI for children on family income and parental behaviour, but neither sheds light on the extent to which benefits compensate the families for the extra cost of disabilities. The first of these studies found that SSI plays a significant role in helping families with disabled children stay out of poverty. According to Lukemeyer *et al.*, with the exception of families receiving SSI, families caring for a special-needs child had poverty rates two to eight percentage points higher, depending on severity, than those of families with healthy children only. Families that received SSI benefits for their children experienced significantly lower rates of poverty. Among SSI families with severely disabled children, 42 per cent had household incomes below the official poverty line, including 20 per cent with incomes below 75 per cent of the poverty line. In contrast, 82 per cent of those households with severely disabled children and no SSI benefits had incomes below the poverty line, including 73 per cent with incomes below 75 per cent of the poverty line.

The second study did not find that SSI helps families with disabled children stay out of poverty, however. This study was part of an evaluation of the effects of the 1996 Personal Responsibility and Work Opportunity Act, which tightened the SSI medical eligibility rules for children that were promulgated after Zebley. Rogowski *et al.* (2002) assessed the effects of SSI benefit loss on families whose children lost their SSI benefits as a result of the legislation,⁷ using data from the Survey of Income Program Participants (SIPP). Counter intuitively, they found that family income increased in the short run (four months) and medium run (12 months), although the effect for the medium run was not statistically significant. They also found no increase in the number living in poverty. The authors concluded that the short-term increase in income was most likely a result of increased work effort and greater reliance on other welfare programmes, such as Temporary Assistance for Needy Families (TANF).

The differences in these findings likely reflect differences in methods and the population studied. Lukemeyer *et al.* had to rely on non-exogenous variation in SSI receipt across families, whereas Rogowski *et al.* could take advantage of the exogenous effect of eligibility tightening. This makes the Rogowski *et al.* findings stronger for the population they examined but that population is limited to those families with children who were eligible for SSI on the basis of the rules in place before 1996 but not the post-1996 rules.

⁷ The Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996 modified the definition of disability used to determine eligibility for receiving SSI benefits for children with disabilities.

4.3 Veterans' benefits

The U.S. Veterans Benefits Administration conducts several programmes for veterans with disabilities. The most important of these is Veterans' Compensation (VC), which is designed to compensate veterans for lost earnings capacity because of a service-related disability. VC is distinguished from other earnings-replacement programmes, however, because compensation is paid regardless of how much the veteran actually earns. In essence, it is an allowance programme but the rationale for the programme is not the 'extra cost' of disability; it is perhaps better described as compensation for injuries received while in service to the country. The monthly compensation amount is based on an assessment that rates the level of disability as a percentage of average loss in earning capacity. In 2007, the lowest level of compensation was \$117 a month for a disability rating of 10 per cent and the highest was \$2,527 for a disability rating of 100 per cent. Additional payments are made based on the number of dependants, having a severely disabled spouse and special circumstances such as the loss of a limb.⁸

A much smaller veterans' programme is designed to compensate for the extra cost of disability. Aid & Attendance (A&A) is available to low-income wartime veterans or surviving spouses – including those with non-service-related disabilities – who are either 100 per cent disabled and under age 65 or who are over 65 and (1) require the aid of another person to perform personal functions required in everyday living (2) are bedridden (3) are patients in a nursing home due to mental or physical incapacity or (4) are blind or nearly blind. Similarly, Housebound benefits are paid to low-income veterans who either (1) have a single permanent disability rated at 100 per cent and are confined to their immediate premises; or (2) have a single permanent disability rated at 100 per cent and another disability evaluated at 60 per cent or higher.

In 2008, the maximum countable income for eligibility purposes is \$18,654 (no dependants) or \$22,113 (one dependant) and assets must be valued at less than \$80,000 excluding the veteran's home and one vehicle. The allowance is the difference between countable income and the maximum countable income, up to \$11,181 per year (or \$932 per month) for an individual with no dependants and \$14,643 per year (or \$1,120 per month) for an individual with one dependant. Although A&A and Housebound benefits are intended to help pay for the extra cost of disability, the amount of the allowance is based on household income remaining after medical expenses, not an estimate of the extra costs per se (Veterans' Disability Benefits Commission, 2007). In essence, these programmes use income after medical expenses as a standard of living measure and help veterans and survivors with disabilities attain a benchmark value.

There are a number of other benefits to help cover the additional costs of disability for eligible veterans. These include a clothing allowance, grants for specially adapted housing and grants for automobiles or adaptive equipment.⁹

⁸ Veterans Compensation Benefits Rate Tables (1 December 2007).

⁹ See Fact Sheets at www.va.gov. We were unable to find documentation on how allowance amounts are determined.

5 Evidence from other programmes and research

In this section, we discuss four papers that use 'expenditure equivalence' to estimate the extra cost of disability. The basic question in this approach, as mentioned in Chapter 2, is how much extra income a person with a disability needs to achieve a specified standard of living based on a measure that does not use income as a direct input. The first two papers are based on data from Ireland and build on the approach of Berthoud *et al.* (1993) and Zaidi and Burchardt (2005) to estimate the extra cost of disability. The two remaining papers are based on data from the United States and Australia, respectively.

Indecon (2004) used the 1999/2000 Household Budget Survey (HBS), the Irish equivalent of the UK Family Expenditure Survey, to estimate the extra cost. The HBS is representative of all private households in Ireland and has been carried out periodically since 1951. The 1999/2000 wave included 7,644 households and the study included 5,601 households containing only non-pensioner individuals up to age 65.

Disability in the Indecon study was measured at the household level based on whether households were receiving any disability-related payments. This is a significant weakness of this study as many employed individuals and children with disabilities are not eligible for such disability-related payments. The researchers were also unable to provide extra-cost estimates by severity of disability or for pensioner households (aged over 65 years) because of data limitations.

For the Indecon study, the authors used a composite measure of the standard of living based on goods, activities and assets that they judged to be of essentially equal value to the household, regardless of whether it contained an adult with a disability: household ownership of a dishwasher, a deepfreeze, a bank account, a car, a tumble dryer, a personal computer; household savings; and taking an in-country holiday in the previous year. The premise that these items are of equal value to both types of households is arguable (e.g., a single person who is severely vision impaired would presumably place less value on car ownership than a similar person without a disability). The study estimated an extra cost of disability of €143

per week, about 23 per cent of household disposable income, at the median weekly level of income; that is, a household containing a member with a disability would need to spend €143 more than a comparable household without a member with a disability to achieve the same standard of living. The extra-cost estimate at the mean weekly level of income was €136, about 20 per cent of disposable income.

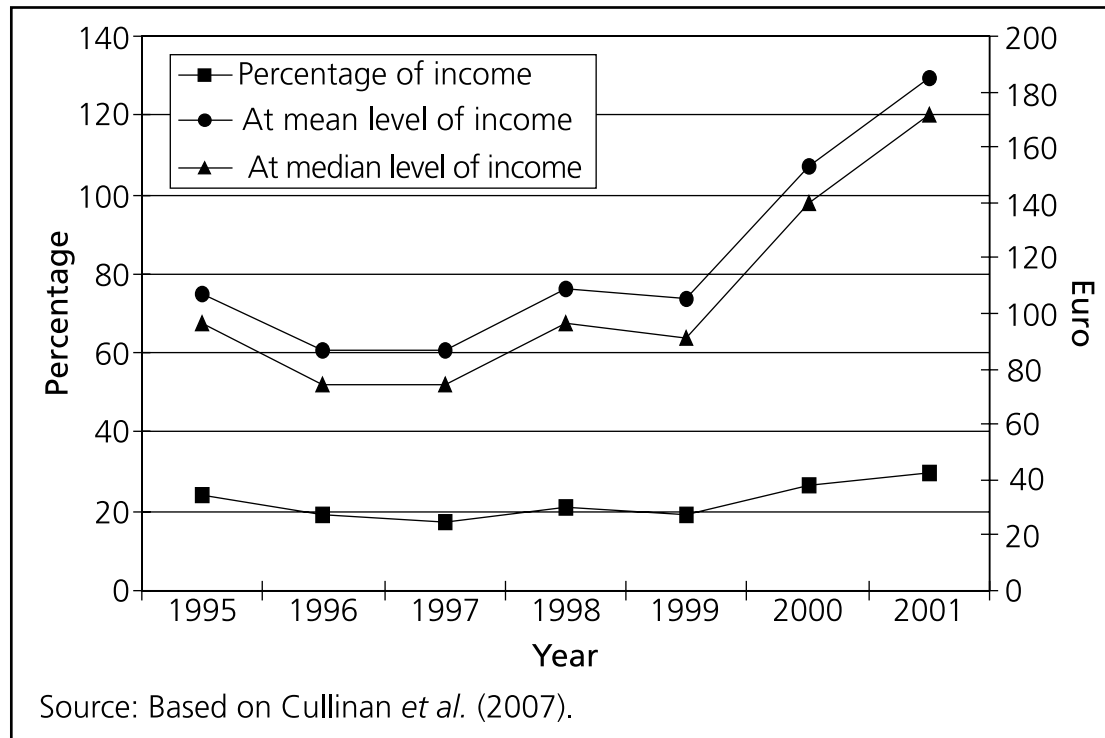
Cullinan *et al.* (2008) used data from seven rounds of the Living in Ireland survey from 1995-2001 and included a sample of 17,621 individuals representative of private households in Ireland. The authors used a composite measure of the standard of living similar to the Indecon study, based on household ownership of a number of non-disability-related durable goods and also on whether the household took a holiday the year before the survey. The authors reported that the extra-cost estimates were robust to changes in the subset of indicators and in methods used to create the composite measure. Their method for identifying people with disabilities was much different than in the Indecon study, however; it was based on a response to a simple survey question. The survey question is, 'Do you have any chronic physical or mental health problem, illness, or disability?'

For 2001, the authors estimated an extra cost of €129 of weekly disposable income at the median level of income and €172 of weekly disposable income at the mean level of income. For the full sample of households, the extra cost of disability as a percentage of weekly disposable income over seven years was about 30 per cent. Figure 5.1 shows the trend in extra cost of disability over the sample years.

In 2001, the estimated extra cost of disability for the most severely disabled group was 44 per cent of weekly disposable income compared to 9 per cent for those least severely disabled.¹⁰ At the median level of income, these estimates were €164 and €56, respectively, and at the mean level of income they were €250 and €67, respectively. The estimated extra cost for a pensioner household where the head is over age 65, was 25 per cent of weekly disposable income compared to 38 per cent for a non-pensioner household in 2001. These estimates were €71 and €228 at the median level of income and €101 and €274 at the mean level of income, respectively.

¹⁰ Severity of disability represents the extent to which individuals are restricted in performing daily activities and is based on responses to the question, 'Are you hampered in your daily activities by this physical or mental health problem, illness, or disability?' Response choices were: (a) yes, severely; (b) yes, to some extent; or (c) no.

Figure 5.1 Trends in estimated extra cost of disability in Ireland, 1995–2001



The next two papers use measures of ‘material hardship.’ They compare the prevalence of hardship for those with and without disabilities, holding income and some other factors constant.¹¹ They then use estimates of the effect of income on the prevalence of hardship to impute the extra income that those with disabilities would need to reduce the prevalence of hardship to the same level as those without disabilities.

She and Livermore (2007) used the 1996 panel of SIPP, a nationally representative sample of the civilian non-institutional U.S. population. The SIPP includes 12 interviews conducted between 1996 and 1999. The authors used a longitudinal sample of 26,433 individuals aged between 25 and 61 at the time of first interview. Hardship is measured in several ways. These include indicators for inability to meet specific essential expenses (for example, rent or mortgage payments and utility bills), inability to obtain needed medical and dental care and food insecurity (for example, going hungry and missing meals).

The authors found that individuals with work limitations are much more likely to experience hardships than people without work limitations living in households with comparable incomes. They used their estimates to calculate how much extra income a household with income at the U.S. poverty line and containing an adult with disabilities would need to reduce the probability of measured

¹¹ These papers actually are answering the question of what extra amount of income is necessary to avoid or experience a certain level of disutility (hardship).

hardship to the same value as comparable households that do not include an adult with disabilities. This exercise yielded estimates of extra cost of disability from \$16,500 to \$28,800 per year for an individual under age 65 with a disability of at least 12 months' duration, depending on the hardship measure used; this was compared to a poverty threshold of just over \$10,000 (in 2005) for the same type of household without disability. This extra cost is in addition to any extra costs paid for by government programmes. The authors calculated disability adjusted poverty standards for different types of limitations and different types of hardship (Table 5.1).¹² The difference between the poverty standard for those not reporting and those reporting a work limitation is the estimated extra cost of disability. The amount varies, depending on when the work limitation was reported relative to when the respondent was asked about hardship and, if asked in the same year, the duration of the work limitation.

Table 5.1 Disability-adjusted poverty standards for a family size of one

Work limitation	Didn't meet expenses	Didn't pay rent or mortgage	Didn't pay utility bills	Didn't get needed medical care	Didn't get needed dental care	Food insecure	Any hardship
None	\$10,160	\$10,160	\$10,160	\$10,160	\$10,160	\$10,160	\$10,160
Yes*	\$32,852	\$25,345	\$28,441	\$38,977	\$36,765	\$26,668	\$33,478

Source: Livermore and She (2007).

*Work limitation of at least 12 months and reported in the year during which the hardship questions were asked.

The She and Livermore study has several limitations: First, disability is measured at the individual level, while poverty and hardship are measured at the household level. Thus, statistics calculated in this study do not take into account the possibility of having more than one individual with disability in the household. The authors conclude that this limitation has a negative effect on the estimated extra cost of disability. Second, the study measures extra cost only for working age populations in the labour force. Children and retired older people, who form a significant portion of the population with disability, are not included in the study.

Saunders (2006) attempted to replicate Zaidi and Burchardt's (2005) UK study on the extra cost of disability using data from the Australian Household Expenditure Survey (HES) for 1998/99, which contains information on material hardship. Disability is measured at the household level, which overcomes the limitations in the She and Livermore study. Incidence of hardship, the material hardship measure, is calculated by counting positive responses to a series of hardship questions.

¹² The results reported here are for persons who reported work limitations of at least 12 months' duration during the same year in which they were asked about material hardship. The authors also present estimates for those reporting work limitations of shorter duration in the same year and work limitations in other years.

Based on their multivariate analysis, Saunders calculated that the extra cost of having at least one household member with a disability is about 37 per cent of disposable income; that is, a household containing a member with a disability would need 37 per cent more income than a comparable household without such a person to reduce the incidence of hardship to the same level. Saunders also calculated extra cost classified by severity of activity restrictions caused by disability. Additional analyses found that the extra cost of disability increases with the severity of disability. For the most severe category ('profound'), the extra cost is between 40 and 49 per cent of household income.

Table 5.2 (from Saunders) shows poverty rates of different types of households with and without a member with a disability. The first two columns show rates that have not been adjusted for the extra cost of disability. The third and fourth columns show rates that have been adjusted. The adjustment reduces the poverty rates for households without disabilities because the poverty standard is half of median income and the adjustments for households with disabilities have the effect of reducing median income. For all types of households considered together, the poverty gap rises from an unadjusted 1.6 percentage points to an adjusted 25.2 percentage points.

All of these studies, as well as Zaidi and Burchardt's (2005) UK study, show that the extra cost of disability, based on their respective standard of living proxies and disability definitions, is very high. Estimated costs appear to be much higher in the U.S. than in the other two countries. That might reflect institutional differences – most notably the absence of universal health care in the U.S. – but also might be attributable to methodological differences.

Table 5.2 Disability non-adjusted and adjusted poverty rates, by household types (percentages)

	Poverty rates before adjusting for disability		Poverty rates after adjusting for disability	
	No disability	With a disability	No disability	With a disability
Single, non-aged	11.3	21.2	5.7	53.7
Single, aged	13.2	12.4	7.0	59.1
Couple, non- aged	3.7	6.7	2.9	24.5
Couple, aged	3.6	6.2	2.4	39.5
Couple with children	4.9	6.7	3.3	15.4
Sole parent	15.8	10.3	8.0	29.6
Mixed family household	5.9	4.5	5.2	8.5
All households	7.4	9.0	4.5	29.7

Source: Saunders (2006).

Notes: Poverty rates are defined as 50 per cent of median income for all households.

6 Conclusion

Governments routinely help people with significant disabilities to improve their standard of living by paying, in various ways, for goods and services that compensate for those limitations. Allowance programmes are a conceptually appealing way to pay for such goods and services. Their intent is to provide recipients (individuals or families) with financial resources that they can use in a flexible and efficient manner to improve their own lives. There is strong evidence that allowance programmes can outperform other programmes that pay directly for specific services. The experimental C&C demonstration in the U.S. found that, in a variety of circumstances, allowances, accompanied by counselling, led to improvements in the lives of recipients relative to status quo systems under which the government paid directly for services purchased from qualified agencies. The demonstration programmes were somewhat more expensive than the existing programmes but that reflected the size of the allowances given, as well as the fact that participants in the existing programmes often failed to receive the services for which they were eligible because of administrative obstacles.

We have collected and examined information about numerous allowance programmes outside the UK. We have not found information about how these programmes determine the size of their allowance payments or assess their adequacy in covering the extra costs of disabilities. We surmise that these programmes initially set allowance rates on the basis of some notion of reasonable expenses for relevant services (most often personal assistance), with adjustments in later years that reflect inflation and political and fiscal realities. The establishment of the allowance rates for the C&C demonstration programmes is illustrative; in each case the relevant government agency initially based the amount of the allowance on the services for which the recipient would be eligible under the traditional programme and the costs of those services.

If the objective of allowance programmes is to efficiently help recipients raise their standard of living, then the conceptually appropriate way to set the amount of the allowance would be to estimate how much additional income recipients would need to increase an operational measure of their standard of living to some target level. Fiscal constraints might prevent the programme from offering sufficient allowances to attain the targeted standard of living, but this approach would at least establish a benchmark for assessing the adequacy of the allowances offered.

One practical impediment to following this approach is that most standard of living measures are based on household income, adjusted for household composition. Such measures cannot be used in this context, because households containing individuals with disabilities experience a lower standard of living than comparable households with the same income. Put differently, households containing individuals with disabilities need more income to attain the same standard of living as households that contain no such individuals, but are otherwise comparable. The amount of the additional income is one definition of the extra cost of disability – the expenditure equivalence definition.

Given the objective of allowance programmes, the expenditure equivalence definition of the extra cost of disability is conceptually preferred to definitions based on the cost of extra goods and services actually used by a household, or expenses for extra goods and services required for recipient households to engage in the same array of activities as otherwise comparable households. If the household is paying the full price for extra goods and services, these two methods yield estimates of the extra cost of disability that are too low and too high, respectively.

Only a few studies have used the expenditure equivalence approach to measure the extra cost of disability, in the UK, Ireland, U.S. and Australia. All of these studies found that the extra costs of disability are very large when expressed as a share of household income.

Although the conceptual definition of the extra cost of disability in these studies is pertinent to the purposes of allowance programmes, none provide a sound basis for assessment of the adequacy of the allowances provided by the AA and DLA programmes. With the possible exception of the UK and the Irish studies, they use operational measures of the standard of living that are likely to be unsuitable for these programmes. In addition, they are based on more broadly defined disability populations than those targeted by AA and DLA and, again with the possible exception of the UK study, apply to people living in very different economic and policy environments than those in which AA and DLA participants find themselves.

Although the evidence from these studies is not immediately helpful, they do point the way toward research that could inform future efforts to assess AA and DLA. It might be feasible, for instance, to repeat the analysis of Zaidi and Burchardt in a manner that is tailored to the information needs of the AA and DLA programmes – focused on the right target populations and using standard of living measures suitable for programmatic objectives. In any such study, the AA and DLA allowances received by study subjects would need to be counted as household income. Failure to do so would likely lead to underestimates of the extra cost of disability, because such households presumably are using these allowances to improve their standard of living.

A more ambitious study would involve including supplemental samples of households that receive AA and DLA payments in a national expenditure survey being conducted for broader purposes. The data for these subjects could then be compared directly to data for comparable subjects without disabilities in the main survey sample. The main advantages of this study, relative to a study that uses available data only, are that DWP would have programmatic information on current participants and the sample sizes of current participants would be much more substantial. Another advantage is that this study would allow DWP to observe directly how current recipients of AA and DLA are faring on a variety of measures. Such information might be quite informative for purposes of any effort to better understand these allowances.

Appendix A

Summary of major United States disability programmes

Table A.1 Major United States programs for people with disabilities

Programme	Description	Target population	Number of participants	Funding source
General cash disability programmes				
Social Security Disability Insurance (SSDI)	Programme to insure workers and their dependents against loss of income due to disability. Payments are based on individuals' lifetime average earnings covered by Social Security. Spousal and children's benefits are subject to family maximum	Adults with disabilities with sufficient SSDI-covered earnings history and their dependants (spouse, children)	6.8 million workers, 0.2 million spouses, 1.7 million children (2006) (SSA, 2008)	Federal (payroll taxes)
Supplemental Security Income (SSI)	Means-tested programme (with both income and asset screens) to provide monthly cash income to people under 65 who are blind or disabled ^a	Blind people and people with disabilities of any age with limited income and assets	Federal and state blind and disabled: 6.0 million adults (December 2006) (SSA, 2008)	Federal (general revenues), state fund supplement
Health insurance				
Medicare	Provides health insurance coverage to qualified disabled and elderly individuals	Workers who have received SSDI for at least 24 months and almost all legal residents age 65 and over	6.9 million SSDI beneficiaries (July 2006) (CMS, 2008)	Federal (payroll taxes)
Medicaid	State health insurance coverage offered under federal rules and partially funded by the federal government, including supplemental coverage for low-income Medicare enrollees	Legal residents who are low income children, their parents, people with severe disabilities (including most SSI recipients) or age 65 or older	8.3 million persons with disabilities under age 65 (2005) (Kaiser Family Foundation, 2008)	Federal (general revenues)/ state (general revenues)
				Continued

Table A.1 Continued

Other disability support programmes for specific subpopulations				
Workers' Compensation	Cash payments, rehabilitation services, and medical benefits provided by employers to workers who suffer work-related injuries or diseases and to their survivors (in case of fatality). Optional in Texas only	People who suffer work-related injuries and diseases or their survivors	Unavailable	Employer premiums, though some employers self-insure
Department of Veterans Affairs (VA) Programmes	Programmes including: disability compensation payments for veterans with service-related injuries, pensions for low-income veterans with disabilities for any reason, health care and allowances for disability-related goods and services	Veterans with service-related disabilities, other disabilities, or age 65 and over (depending on the benefit)	2.9 million veterans receiving disability compensation (December 2007) (U.S. VA, 2008)	Federal
Return-to-work support programmes				
State Vocational Rehabilitation (VR)	Programme intended to help people with physical and mental impairments to work by providing services including medical and therapeutic services, counselling, education, training, and job placement assistance	Adults with physical or mental impairments who are able to benefit from VR services	Served 1.4 million consumers (2004) (U.S. Department of Education, 2007)	Federal-state match (match requirement is 21.3 per cent)
State Workforce Development Systems	Programme mandated by the Workforce Investment Act (WIA) of 1998 that requires states to integrate job training adult education and literacy, and VR programmes into a one-stop delivery system	All adults and youth who meet state-determined criteria	20,000 adults with disabilities and 23,800 youth with disabilities exited WIA services (2005) (SPRA, 2007)	Federal-state match

Source: Updated from Wittenburg and Favreault (2003).

^a SSI also provides benefits to those age 65 and older with limited incomes and children under age 18 who meet specific disability and income requirements.

^b National beneficiary estimates are not available because of how workers' compensation data are managed; for an overview, see Sengupta *et al.*, 2007. In 2005, 128.1 million workers were covered under workers' compensation (SSA, 2008).

Appendix B

Summary of disability allowance programmes from selected countries

We collected summary information on allowance programmes in developed countries based on reports and data tables from the European Commission, OECD, and U.S. Social Security Administration reviews of social security systems throughout the world, as well as readily accessible programmatic fact sheets and websites. Unfortunately, specifics on many of the selected programmes are not readily available. A small number of benefit programmes were found that address the care needs and financial burdens experienced by individuals with disabilities.

Although our interest was in programmes that provide allowances for the extra cost of disabilities, it is sometimes hard to distinguish between such programmes and those that provide income supplements to low-income households. In some instances, we also found that allowances for the extra cost of disability are sometimes tied to income supplement programmes. Hence, not all of the programmes described here are purely allowance programmes for the extra costs of disability.

For ease of comparison to the UK DLA and AA programmes, all benefit rates have been converted into British pounds per week using the exchange rates from xe.com as of 3 April 2008.

Country: Australia

Name of programme(s):

Carer Allowance

Carer Payment

General description:

Carer Allowance: Intended to assist carers who provide daily care and attention to adults with disability, severe medical conditions or who are frail and elderly and living in the community.

Carer Payment: Intended to provide financial support to people providing constant care to a person with a disability receiving income support.

1. Qualifying conditions/limits

- Carer Allowance: Provides daily care and attention at home. Ten-year residency requirement for care provider and disabled individual. No income test.
- Carer Payment: Provides constant care. Ten-year residency requirement for care provider and disabled individual. Means-tested for both carer and receiver.

2. Assessment

- Assessment of care needs of persons with a disability.

3. Needs met

- Income supplement.

4. Provisions

- Cash benefit. Carer allowance equals 101 AUD every two weeks (£23 per week). Carer payment equals up to 547 AUD every two weeks (£125 per week). If eligible, may receive both benefits.

Country: Belgium

Name of programme(s):

Integration Allowance (allocation d'integration/integratietegemoetkoming)

Allowance for Assistance to the Elderly (allocation pour l'aide aux personnes agees/tegemootkoming voor hulp aan bejaarden).

General description:

Intended to assist with the extra costs arising from functional impairments to guarantee financial protection to persons with a disability.

1. Qualifying conditions/limits

- Nationality and residency requirements. Not payable in conjunction with certain other benefits. The Integration Allowance applies to those aged 21-65. The Allowance for Assistance to the Elderly applies to those over 65. Means-tested.

2. Assessment

- Assessment for limitations to Activities of Daily Living and Instrumental Activities of Daily Living that affect independence.

3. Needs Met

- Extra costs due to functional impairments in the areas of: mobility, preparing and eating food, personal care and hygiene, household tasks, living without supervision, communication and social contact.

4. Provisions

- Cash benefit. Five rates, dependent on level of impairment and age. Integration Allowance (aged 19-65) ranges between 1,000 EUR and 9,000 EUR per year (£15-135 per week). Allowance for Assistance to the Elderly (over 65) ranges between 854 EUR and 5,737 EUR per year (£13-86 per week).

Country: Denmark

Name of programme(s):

Disablement Supplement (replaced a number of individual disability benefits available prior to 1 January 2003)

General description:

Intended to compensate for extra costs resulting from disability.

1. Qualifying conditions/limits

- Expected extra costs must exceed €806 a year (£632). Three-year residency requirement for Danish nationals and ten years for foreign nationals. No income test.

2. Assessment

- Assessment of functional capacity.

3. Needs met

- Extra costs resulting from the disability, including extra transport costs.

4. Provisions

- Cash benefit. Amount considers individual's expected expenses.

Country: Hong Kong

Name of programme(s):

Disability Allowance

Disability Benefit

General description:

Disability Allowance: Intended to provide a monthly allowance to individuals with severe disabilities.

Disability Benefit: Intended to provide a safety net by assisting with the special needs of low-income individuals with disabilities.

1. Qualifying conditions/limits

- Disability Allowance: Seven-year residency requirement. No income test. Lower rate – 100% loss of earning capacity or profoundly deaf. Higher rate – requires constant attendance. No income test.
- Disability Benefit: Seven-year residency requirement. Means-tested.

2. Assessment

- Disability Allowance: Assessment by Director of Health or the Chief Executive of the Hospital Authority determines 'severely disabled.'
- Disability Benefit: Assessment by a public medical officer.

3. Needs met

- Disability Allowance: Helps meet the special needs arising from severe disability.
- Disability Benefit: Supplement to help meet the needs of people with disabilities.

4. Provisions

- Disability Allowance: Cash benefit. Lower rate – 1,125 HKD per month (£18 per week). Higher rate – 4,165 HKD per month (£67 per week).
- Disability Benefit: Cash benefit. Amount dependent on living situation, age, degree of disability, and attendance requirements. Between 1,930 HKD and 4,165 HKD per month (£124-67 per week), if living alone. Between 1,750 HKD and 3,850 HKD per month (£28-62 per week), if living with family. Special grants available to meet specific individual needs.

Country: New Zealand

Name of programme(s):

Invalids Benefit

Disability Allowance

General description:

Invalids Benefit: Intended to provide assistance to people who are unable to work due to sickness, injury, or disability.

Disability Allowance: Intended to provide non-pension beneficiaries assistance with additional expenses because of disability.

1. Qualifying conditions/limits

- Invalids Benefit: Restrictions in work ability. Ten-year residency after age of 20 requirement. Means-tested.
- Disability Allowance: Intended to provide non-pension beneficiaries assistance with additional expenses because of disability. Means-tested.

2. Assessment

- Invalids Benefit: Assessment for inability to work regularly 15 hours or more a week over the next two years, or total blindness.
- Disability Allowance: Assessment of disability-related expenses.

3. Needs met

- Invalids Benefit: Assist with meeting living costs.
- Disability Allowance: Ongoing regular costs attributable to disability.

4. Provisions

- Invalids Benefit: Cash benefit. Amount depends on living and family situation. Between 181 NZD and 286 NZD per week (£71-112 per week).
- Disability Allowance: Cash benefit. Amount depends on individual expenses. Between 441 NZD and 742 NZD per week (£173-292 per week).

Country: Norway

Name of programme(s):

Basic Benefit (grunnstonad)

Attendance Benefit (hjelpstonad)

Other provisions under the National Insurance Act (Folketrygdløven)

General description:

Basic Benefit: Intended to assist with the expenses due to permanent illness, injury or deformity.

Attendance Benefit: Intended to cover the need for special attention or nursing required due to a disability.

Other NIA provisions: Intended to provide financial support for technical aids and services that can provide 'improved functioning in daily life' for persons with a disability (Sections 10-6, 10-7).

1. Qualifying conditions/limits

- Basic Benefit: No minimum contribution to insurance system required. No income test.
- Attendance Benefit: No minimum contribution to insurance system required. No age restrictions. Means-tested.
- Other NIA provisions: Information not found.

2. Assessment

- Basic Benefit: Information not found.
- Attendance Benefit: Information not found.
- Other NIA provisions: Assessment for a long-lasting disability and verification that a technical aid or service is necessary to improve function and/or break social isolation.

3. Needs met

- Basic Benefit: Extra expenses due to 'permanent illness, injury, or deformity.'
- Attendance Benefit: Special attention or nursing services.
- Other NIA provisions: Expenses for technical aids and other necessary and appropriate aids used to improve functioning.

4. Provisions

- Basic Benefit: Six rates of benefit according to level of extra expenses, ranging between 6,864 NOK and 34,380 NOK per year (£13-65 per week).
- Attendance Benefit: Standard rate is 12,312 NOK per year (£279 per week).
- Other NIA provisions: Grants of up to 100 per cent of the cost of technical aids to individual users.

Country: Sweden

Name of programme(s):

Assistance Allowance (assistansersättning)

Handicap Allowance (handikappersättning)

Car Allowance (bilstod)

General description:

Assistance Allowance: Intended for persons with severe functional disabilities and in need of significant levels of personal attention or assistance.

Handicap Allowance: Intended to assist persons disabled in such a way that they require special help or have special expenses because of the handicap.

Car Allowance: Intended to assist individuals with a disability adapt and/or purchase a car if they cannot use public transportation because of disability.

1. Qualifying conditions/limits

- Assistance Allowance: Attention or assistance required for more than 20 hours per week. Aged below 65. No income test.
- Handicap Allowance: Aged 19-65. No income test.
- Car Allowance: Based on residence. Cannot use public transportation because of disability. Aged 18-65 years. No income test, except for supplement.

2. Assessment

- Assistance Allowance: Assessment for severe functional disabilities.
- Handicap Allowance: Blind or deaf are always entitled to allowance. Assessment to translate individual's care needs into minutes and hours. No standardised time allocations for different needs. Consumer price information is often used to assess extra costs for food, clothing, etc.
- Car Allowance: Assessment for ability to move around, either on their own or by using public transportation.

3. Needs met

- Assistance Allowance: Personal attention or assistance with care needs.
- Handicap Allowance: Assistance with personal care and housework. Cost related to housing, food, etc. Extra costs of living due to disability, such as home adaptations, special appliances, food, clothes and other consumption items, extra medical costs.
- Car Allowance: Assist with the purchase of a car for personal use. Costs for adaptation of a car.

4. Provisions

- Assistance Allowance: Up to 27,141 SEK per year (£44 per week). Municipality will decide amount of benefit.
- Handicap Allowance: Cash allowance paid at three levels, dependent on needs: 69 per cent, 53 per cent, or 36 per cent of the price base amount (40,300 SEK in 2007, £3,380). Maximum amount 2,137 SEK per month (£45 per week).
- Car Allowance: Basic benefit of 60,000 SEK (£5,032). Income test for a supplement up to 40,000 SEK (£3,355). Costs for adaptation of a car due to a person's physical needs are covered without limit. Payable every seven years for purchase or maintenance of a vehicle.

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