

Supports for families with a child with a disability

Research Report

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Executive summary

Objectives

The objective of this study is to examine and document:

- Support for families with a child with a disability in other countries, with a focus on cash supports
- The existence of similar payments to the Domiciliary Care Allowance (DCA) for families with a child with a disability in these countries
- What these similar payments are designed to cover, how they are claimed and how these payments interact with other payments to families with a child with a disability.

Key findings

Part 2 summarises some of the key features of the payments in the six countries studied (Belgium, Canada, Finland, France, Netherlands and the UK) including their objectives; and the structure and function of the schemes, including their interaction with other payments and services. The national schemes are discussed in more detail in part 3 and annex 1.

In general the objectives of the payments considered are to contribute to the additional costs of a child's disability. All of the schemes, except Canada, are based on a combination of the existence of a disability and the associated need for care. There is a significant variation between the various schemes in the levels of payments provided. The Netherlands scheme provides the lowest level of payment (€215.80 per quarter) while the French scheme provides the highest possible level of benefit (€1,210.11 per month). Some schemes are flat-rate (such as Canada and the Netherlands) whereas others involve tiered payments.

The ages covered also vary. Most schemes start at birth, although a number are not payable until the age of three. However, it appears that even where benefits are payable from birth, in most countries maximum take-up of the benefit is not achieved until a later age. The maximum ages vary from 15 to 21.

There is a significant variation in the proportion of children covered by the national schemes, from about 1% in France and the Netherlands to over 3.5% in Finland. This may, in part, be attributable to the different definitions used but is also related to the different roles which the benefits play in their national systems.

The function of the schemes varies from country to country. Some schemes, such as the UK Disability Living Allowance (care component) appear to be broadly analogous in function to the Irish DCA. However, others perform a somewhat different function.

In general, most countries concerned required some form of medical assessment to establish that a disability existed. The countries examined adopted varying approaches to the assessment and adjudication of entitlement ranging from examination by medical doctors (Belgium), to decisions by non-medical staff drawing on detailed information as to the impact of the child's disability (UK), to assessment by independent agencies (France and Netherlands).

Relevance to Ireland

The countries examined here have all opted to establish some form of social security (or tax) benefit to assist with the costs of disability. All the European countries have linked this to the need for care which is, in general, defined somewhat similarly to the Irish approach, i.e. as involving a need for care, arising from a specific disability, which is greater than a non-disabled child of the same age. However, the details of the various payments and their role in their national support systems vary greatly. The national schemes have been affected both by the national context and by historical developments. In general, it is not clear that there are very specific lessons for Ireland in terms of the overall design of the benefits, other than that a variety of approaches is possible.

In terms of assessment and adjudication, countries have opted for a number of different approaches. It is clear that making such assessments is a difficult task and it is not apparent that any country has found a perfect solution to assessment and adjudication.

If reform of the existing Irish approach was felt to be desirable, one option might be to move more towards the UK approach with the development of a more detailed application form which would provide more information about the additional care needs of the child. Deciding officers, with appropriate training, could draw on this data and on information as to the details and impact of specific disabilities, with the ability to refer issues to the Department of Social Protection's medical assessors where more detailed medical advice was required on a specific point.

1. Introduction

Terms of reference

The objective of this study is a short research report that describes payments to families with a child with a disability. The report is, in particular, to examine and document:

- Support for families with a child with a disability in other countries, with a focus on cash supports
- The existence of similar payments to the Domiciliary Care Allowance (DCA) for families with a child with a disability in these countries
- What these similar payments are designed to cover, how they are claimed and how these payments interact with other payments to families with a child with a disability.

The study was commissioned by NDA in the context of the establishment of the Domiciliary Care Allowance Review Group¹ and is intended to assist the Review Group in its deliberations.

Methodology

This included

- a review of relevant literature (including review of various online academic databases)
- access to on-line information from social security authorities and others;
- review of detailed evaluations of payments (where these are available);
- research studies in relation to the use of payments and their impact; and
- Contacts with key informants in the chosen countries.

Unfortunately, the research uncovered relatively few detailed evaluations and research studies of the specific payments. We would like to thank the officials in the various institutions contacted for their very helpful response to our queries.

¹ See http://www.welfare.ie/EN/Pages/DCA_Terms.aspx

Scoping exercise on 14 countries

In line with the detailed terms of reference, the researchers carried out an initial mapping of factual information on cash payments in respect of children with disabilities in the following jurisdictions:

EU - Belgium; Denmark; Spain; France; Italy; Luxembourg; Netherlands; Austria; Portugal; Finland; Sweden; UK;

Non-EU – Canada (Ontario), Australia (New South Wales)

A short information note was provided to NDA setting out the basic provisions in these 14 jurisdictions and, from these, six jurisdictions were selected for more in-depth review.

Six countries selected

The six countries selected were: Belgium; Canada; Finland; France; Netherlands; and United Kingdom. The countries were selected on the basis that they had a payment similar to DCA and that the payment appeared to be of relevance to Ireland. The countries were also chosen to ensure a balance of different types of schemes.

Presentation to DCA Review Group

The researchers made a presentation of the initial findings to a meeting of the DCA Review Group on 11 October 2012.

Structure of the report

Part 2 of this report provides an overview of the key findings of this study and draws out their relevance to Ireland. The detailed country studies are set out in part 3 and in the descriptive matrix in Annex 1 of this report.

2. Findings and conclusions

Summary of findings

Schemes

Each of the countries has a scheme which provides support to families of child with disabilities which are broadly analogous to domiciliary care allowance. The descriptions and main features of these schemes are summarised in table 1 below. A more detailed description will be found in part 2 and Annex 1.

Table 1: Supports for children with disabilities

Country	Payment	Description	Qualifying Conditions
Belgium	Allocations familiales majorées pour l'enfant malade ou atteint d'un handicap	Supplementary allowance for children with disabilities under the age of 21, the amount of which varies according to the degree of disability	(i) Physical or mental incapacity; (iii) degree of activity and participation; (iii) consequences for the family (socio-medical scale)
Canada	Child Disability Benefit	CDB is a non-refundable tax benefit for families who care for a child under age 18	A severe and prolonged impairment in mental or physical functions.
Finland	Alle 16-vuotiaan vammaistuki	Disability allowance for persons under the age of 16	An illness or injury that creates a need for care and rehabilitation that lasts at least 6 months and imposes particular strain and requires a greater commitment than the care of non-disabled children of the same age
France	Allocation d'éducation de l'enfant handicapé (AEEH)	Education allowance for a disabled child	Basic payment requires set % of disability. Supplements payable according to costs incurred and level of care required

Netherlands	Care allowance scheme for disabled children living at home (TOG scheme)	The TOG scheme provides financial support for people caring for disabled children between the ages of 3 and 17 who live at home.	A physical or mental disability which results in the child being substantially more dependent on care, assistance and supervision than a non-disabled child of the same age.
United Kingdom	Disability Living Allowance	Payable to people, including children over age 3 months who have personal care needs and over 3 years with mobility needs as a result of severe disability.	Child must require specified levels of care and need more care than a non-disabled child of the same age

It should be noted that the countries also have other payments for the families of children with disabilities which are described in part 2. In particular, the Netherlands and France have systems of personal budgets which may provide a higher level of cash support than the payments mentioned above.

Objectives

In general the objectives of the payments considered in this study are to contribute to the additional costs of a child’s disability. The objectives of the Canadian payment are somewhat more specific in that the support is focussed on low and modest-income families. In general, however, the schemes are not very specific about their scope, i.e. as to which costs of disability are to be met nor as to the proportion of the costs which are to be taken into account. As we will see there are, in practice, significant variations in the scope of the schemes.

Structure and function of the schemes

All of the schemes, except Canada, are based on a combination of the existence of a disability and the associated need for care. The Canadian scheme, in contrast, is based on the existence of a severe and prolonged impairment in mental or physical functions. Most schemes are universal and generally are not subject to income tax. However, the Belgian scheme is insurance-based while the Canadian scheme is a non-refundable tax credit.

There is a significant variation in practice between the various schemes and in the levels of payments provided. The Netherlands TOG provides the lowest level of payment (€215.80 per quarter) while the French scheme provides the highest possible level of benefit (€1,210.11 per month).

Some schemes are flat-rate (such as Canada and the Netherlands) whereas others involve tiered payments. Here again there is a difference between countries, such as

Finland and the UK, which have a small number of tiers and those, such as Belgium and France which have more complex schemes. In addition, there is a wide degree of variation between the minimum and maximum payments. In the UK, for example, the maximum level of DLA (care component) is about three times the minimum level while the maximum French benefit is almost 10 times the basic payment. Each country assesses the need for a higher level of payment in different ways. In the UK and Finland, this is based on the level of care required. In France it is also based on the level of care but linked to the need to provide care (and whether the parent(s) give up work to provide such care). The Belgian system is based on the points scored over a complicated assessment of disability and its impact.

The ages covered also vary. Most schemes start at birth, although a number are not payable until the age of three. However, it appears that even where benefits are payable from birth, in most countries maximum take-up of the benefit is not achieved until a later age. The maximum ages vary from 15 to 21. In general children who exceed the age limit may qualify for an adult costs of disability payment (where this exists) and/or for an income maintenance payment (either a disability allowance or a minimum income payment). However, there is generally no provision for an 'automatic' transfer to an adult payment.

There is also a significant variation in the proportion of children covered by the national schemes, from about 1% in France and the Netherlands to over 3.5% in Finland (see table 2.2 below). This may, in part, be attributable to the different definitions used but is also related to the different roles which the benefits play in their national systems.

The function of the schemes varies from country to country. Some schemes, such as the UK DLA (care component) appear to be broadly analogous in function to the Irish DCA. However, others perform a somewhat different function. For example, the higher levels of the French benefit are intended to provide compensation for loss of income due to the need for a parent to care for the disabled child.² In addition, the function of some of the benefits appears to have been shaped by other developments in national policy. For example, while the structure of the Netherlands TOG benefit looks rather similar to the Irish DCA, in practice, the TOG is set at a comparatively low level and plays a rather limited role in the Dutch system when compared with the much more significant personal budget (PGB).

Therefore, although the six benefits considered here look similar they do not fulfil the same function in their national systems and it would be unwise to consider them comparatively without taking into account the broader level of supports provided.

² Somewhat analogous to the carer's benefit in Ireland.

For ease of comparison we set out below the proportion of children covered and the level of expenditure (as % of GDP) of the six schemes. However, for the reasons set out above, this should not be taken as an overall indication of the level of support available to disabled children in the respective countries. Unfortunately we have not located any recent comparative studies of the level of social supports provided to disabled children in the countries concerned and any overall estimate of the numbers supported and total cost would involve significantly more work than is possible within the context of this study.

Table 2.2: % of children covered and costs as % of GDP (most recent year available)

	B	C	Fin	Fr	N	UK	Ire
% of children in receipt of benefit	1.6	[n/a]	3.7	1.2	1.0	2.9	2.5
Costs of benefit as % of GDP	0.046	0.017	0.038	0.040	0.004	0.088	0.063

Bearing in mind these limitations, the table above sets out the percentage of children (in the relevant age group) in receipt of benefit in each country. This ranges from a low of about 1% in France and the Netherlands to over 3.5% in Finland. As a percentage of GDP, expenditure on these schemes is understandably very low (below 0.1%). However, in comparative terms it does give some indication of the level of resources expended. The Netherlands expenditure is by far the lowest (0.004% of GDP) but this is misleading as, if expenditure on the PGB is included, the level of support would be much higher. The highest level of expenditure is in the UK (0.088%) (as a result of the comparatively high number of children covered and the high rate of benefit). Although Finland had the highest percentage of children covered, its average rate of benefit is not very high (in comparative terms) so its overall expenditure is mid-table (0.038%).

Intra-country variation

We noted above that there is significant variation between countries as to the proportion of children covered by the national benefit. However, there is also a significant level of variation *within* countries. In France, for example, while on average about 1% of the child population receive the AEEH, this varies from 0.4% in some départements to 1.7% in others.³ A recent French study stated that the reasons

³ The average amount of the benefit also varies significantly by department from a low of €197 to a maximum of €485 (DREES, 2007).

for these variations were difficult to understand (CNAF, 2009). It proposed that the existence of schools and supports for disabled children (which may vary by département) could be one contributing factor. However, it suggested that the local economic context could also play a role.

Similarly, Belgian research has identified significant variation in the proportion of disabled children awarded benefit between the different social security funds which administer the Belgian social security system. There is a correlation between the number of invalidity pensioners insured with a fund and the level of awards to disabled children (ONAFTS, 2008).

A UK study has also identified significant variations in the award of DLA (Care component) by region and social class (Roberts and Lawton, 1998). This study found that disadvantaged families were less likely to apply for the care component, less likely to receive an award, and more likely to receive the lower rate of DLA. It also found regional variations in awards and suggested that the adjudication system was not dealing with applications consistently.

Impact of the payments

Detailed studies of the impact of the payment have been located for the UK only. These studies showed that parents spent DLA on needed equipment or activities and on treatment and tuition (Corden et. al., 2010). Some parents had heavy expenditure on heating, electricity, transport and costs of maintaining or replacing appropriate clothes and shoes and reported that having DLA helped them to pay for such items and services. Parents on low incomes said that without DLA their children's lives would be adversely affected, for example, spending less on items needed for their disabled child. The more generally reported effect would be a reduction in living standards for the whole family

Interaction with other payments and services

In the national reports (in part 3) we have set out a short description of the national context and services provided for children with disabilities. However, there do not appear to have been any detailed or quantitative studies of the countries concerned and it is difficult to obtain a detailed picture of the level or quality of services in each country. In terms of the interaction between the payments studied and other social services, these payments are generally provided by the social security authorities (in Canada the Revenue authorities) whereas social services are provided by different (and often local or regional) bodies. Therefore, it appears that there is limited interaction between the provision of social security and the provision of social services in cash or in kind. In general the social security payments may be spent as the parents see fit and there has been little study in most countries of what they are actually used for. France is an example of a country which is attempting to move towards a more integrated provision of services with the establishment of the

départemental disability centres (MDPH) and the plans to replace the social security payment with a locally funded cash grant focussed on the need for specific services.

Most countries have some form of personalised budgets though in several these are on a small-scale or pilot basis. In the Netherlands, however, the PGB plays a more important role (in terms of number of children covered and level of payment) than the TOG while in France the prestation de compensation du handicap (PCH) is becoming increasingly important.

Carer's payments

Finland and the UK have payments broadly comparable to the Irish carer's allowance. These may be payable in addition to the DCA-type payment in those countries. However, the other countries considered here do not have a directly comparable payment although many address care costs in different ways. In France (PCH) and Netherlands (PGB), the system of personal budgets may provide cash support to families caring for disabled children but the structure of these personalised budgets is very different to the carer's allowance. In addition, in France, the higher rate of the AEEH provides support to parents who give up work to care for their children (somewhat equivalent to the carer's benefit). In countries without a specific carer's allowance, low income carers may qualify for another social security payment, e.g. a minimum income payment.

Adjudication and assessment

Overall assessment process

In general, most countries concerned required some form of medical assessment to establish that a disability existed. The UK does not actually require such certification although it appears that such evidence is often submitted as part of the claim and additional medical evidence is often required by the decision maker.

The countries examined adopted varying approaches to the assessment and adjudication of entitlement. In Canada, where the decision does not involve any assessment of the need for care, the medical certification is reviewed by the relevant agency without (normally) any further examination. Belgium is the only country to require an examination, which is carried out by medical staff employed by the social security agency. It appears that this approach has simply been carried over from the pre-2003 Belgian system which was based on an assessment of the degree of disability (and which has continued in operation on a transitional basis).

In two countries (France and the Netherlands), the assessment is carried out by a separate agency not directly linked to the social security authorities. In the Netherlands the assessment is normally carried out by the CIZ (Centre for Needs Assessment) which is an independent body responsible for carrying out assessments

generally under the Dutch law concerning care (AWZB). In France, assessment is carried out by the Commission des droits et de l'autonomie des personnes handicapées which is a local body established under the 2005 Disability Law. Again this multi-disciplinary agency is responsible for carrying out a range of disability assessments.

Finally, in Finland and the UK, adjudication is (as in Ireland) the responsibility of a non-medical decision maker who is an official of the social security agency. However, the assessment and evidence gathering is carried out in a somewhat different manner to that in Ireland. In the UK, assessment is largely on the basis of a detailed application form, completed by the parent or guardian, which sets out the impact of the child's disability on their need for care and/or mobility. This is reviewed by the decision maker who can seek further medical evidence or advice as necessary. The decision maker operates on the basis of DWP guidance and has access to a detailed on-line database describing the likely impact of different forms of disability.

Levels of award and appeals

Statistics are generally available for the success rate in applications for the relevant payments and these indicate quite a high rate of favourable initial decisions. For example, in France over 90% of initial decisions were favourable.⁴ In Finland and the Netherlands, this was about 80%. However, it is very difficult to compare such national data across countries as the success rates may vary according to persons' knowledge of the qualification conditions, the volume of claims, the precise application process, and how the authorities count applications and categorise outcomes. The success rate for the French PCH is much lower with over 40% of claims being rejected. It may be that this is due to the fact that the PCH is a relatively new benefit or there may be other factors at issue.

Much less data are available for reviews and appeals and problems of comparison are perhaps even greater as appeals systems play different functions in different countries.⁵ However, for the UK about 40% of appeals are successful despite the fact that DLA was established in 1992 and the criteria should, therefore, be clear. While this may suggest some failings in the adjudication system, it again points to the inherently difficult nature of making an assessment of disability and care needs.

⁴ In the UK, Roberts and Lawton (1998) reported success rates of about 90% for child claims for DLA. However, figures for all DLA claims (adults and children) for 2009-10 show 44% of initial claims successful. Data for child claims are not to hand at the time of writing.

⁵ In some countries, as in Ireland, the appeal involves a fresh decision on the case examining the facts. In other countries the appeal is more analogous to judicial review whereby a decision will only be overturned if it is clearly factually incorrect or based on an incorrect interpretation of the law.

Review periods

In terms of reviewing payments, most countries made awards for differing periods depending on the nature of the disability and related factors. These periods varied up to a maximum of five years. The minimum period depends on national law as different countries have different requirements, e.g. in Finland the need for care must last at least 6 months whereas in France the minimum award is for one year. Once the award has expired the child is reviewed again either automatically or at the request of the parents. There is no general practice of reviewing at a specific age.

Relevance to Ireland

General approach

The countries examined here have all opted to establish some form of social security (or tax) benefit to assist with the costs of disability. All the European countries have linked this to the need for care which is, in general, defined somewhat similarly to the Irish approach, i.e. as involving a need for care, arising from a specific disability, which is greater than a non-disabled child of the same age. However, the details of the various payments and their role in their national support systems vary greatly. The national schemes have been affected both by the national context and by historical developments. In general, it is not clear that there are very specific lessons for Ireland in terms of the overall design of the benefits, other than that a variety of approaches is possible.

However, it should be noted that, in some of the countries examined, there does appear to be a move away from the fixed social security payment towards a more flexible and individualised assessment of need through the personal budget in the Netherlands and the prestation de compensation du handicap in France.

Defining the need for care

One issue, in terms of definition, is whether – in the Irish context – a more specific definition of the extra need for care is required. As discussed in part 3, European countries adopt different approaches to this issue. On the one hand, Finland assesses the need for additional care and the legislation refers to ‘weekly’, ‘daily’ and ‘round the clock’ care. However, the law and guidelines do not define these terms more precisely and the Finnish social security officials do not appear to consider that more specific definition is required. In contrast, the Netherlands legislation establishes the average number of care hours which a child needs per week and requires that a child must have care needs totalling at least 10 hours per week. Therefore both approaches are possible.

Assessment and adjudication

In terms of assessment and adjudication, countries have opted for a number of different approaches. It is clear that making such assessments is a difficult task and it is not apparent that any country has found a perfect solution to assessment and adjudication. It is perhaps unlikely that one would want to opt for the Belgian model of examination by medically qualified staff. The approaches adopted by France and the Netherlands of establishing separate disability assessment bodies are very interesting. However, this is clearly an issue with much broader implications and one which could not be adopted only to deal with applications for domiciliary care allowance.

If reform of the existing Irish approach was felt to be desirable, one option might be to move more towards the UK approach with the development of a more detailed application form which would provide more information about the additional care needs of the child. Deciding officers, with appropriate training, could draw on these data and on information (such as that available on the DWP website)⁶ as to the details and impact of specific disabilities, with the ability to refer issues to the DSP's medical assessors where more detailed medical advice was required on a specific point.

⁶ <http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/childrens-medical-guides/>

3. Country reports

In this section we set out the main details of the national schemes in the context of the overall supports to children with disabilities in each country. In line with the Terms of Reference (TORS), each national report starts with a short descriptive section outlining general services for families with a child with a disability in broad terms. We provide here only the main details of the national benefit schemes and a more detailed description of the schemes is set out in a descriptive matrix in Annex 1. Given the focus of the DCA Review Group on the assessment of the benefit, we focus on the details of the national assessment systems.

Belgium

Context

Policy framework

Legislative arrangements are complex in Belgium as they follow the division of authority in relation to major policy issues into regional and community authorities. Many laws, decrees and administrative regulations are operating either at the federal, regional or cultural community levels. The Anti-Discrimination Law of 2007 is the main federal legislation covering discrimination. This includes both direct and indirect discrimination in access to employment, health care, public life and access to goods and services. The Social Rehabilitation Act 1963 established the main federal financial benefit provisions on disability and employment, supplemented and superseded later on by decrees in the three Communities and three Regions. These include provisions on sheltered employment and vocational rehabilitation. Implementation resides with the regional agencies (see below). Since 1989, each Community or Region has the authority to structure the educational system and the delivery system of main parts of the health and welfare provisions.

Institutional arrangements

The federal Secretary of State for People with Disabilities is the national policy point but most disability policy falls within the separate jurisdictions of the Flemish Community, the Walloon Region, the French Community, Commission of the Brussels-Capital Region and the German-speaking Community. There are separate bodies with responsibility for people with disabilities in these areas, i.e. in the Brussels area (Service Bruxellois Francophone des Personnes Handicapées, SBFPH), the Walloon region (L'Agence Wallonne pour l'Intégration des Personnes Handicapées, AWIPH), the Flemish Community (Vlaams Agentschap voor Personen met een Handicap, VAPH), and the German Community (Dienststelle für Personen

mit Behinderung, DPB). For example, in Wallonia, the AWIPH is a public body under the aegis of the Walloon Minister of Health, Social Action and Equal Opportunity. It is responsible for carrying out the Walloon policy concerning integration of persons with disabilities. The family allowance system is administered by the National office for family allowances (ONAFST) through a series of social security funds (*caisses*).

Social services

Social services for children with disabilities in Belgium are generally provided by the regional authorities and there is, therefore, some variation in the provision of services. For example, in the Wallonia region, the AWIPH provides financial support towards the cost of housing and technical aids to encourage disabled children's integration at home, and in school. The CICAT (Centres des Informations et des Conseils en Aides Techniques) is responsible for the coordination of information and advice on technical aids. For disabled children, AWIPH has approved and subsidizes services for preschool assistance. AWIPH has also approved and subsidizes services for assistance toward integration. These have the tasks of collaborating directly with mainstream and special schools (with whom a convention regulating the objectives and methods of working is signed) and of providing educational aids for young people and their parents in order to facilitate social and school integration. Guidance services approved by AWIPH have the objective of assisting disabled people with projects that will increase their autonomy. AWIPH has also initiated a pilot project in personal budgets, with the goal of providing assistance with school activities, recreation, and outside school periods.

Health care

The Belgian system of health care is administered by competing mutual health associations and provided by a mixture of public and non-profit hospitals. The government pays each mutual health association depending upon the number of affiliated members. The Belgian health care system provides for the reimbursement of the cost of various aids and appliances for children with disabilities.

Cash payments for children with disabilities

The Belgian social security system includes an allowance for children with a disability. There has been a long-standing payment as part of the Belgian social insurance system (since 1964). However, until 2003 this was based on the level of disability only. This led to many criticisms as it was argued that (i) many children who needed care did not meet the threshold for the payment and (ii) where a child's ability improved due to the care which was being provided he or she could lose out on the payment as their level of 'disability' fell. As a result a new system was introduced in 2003 which also considered the impact of the disability on the child and his or her family.

The rate of payment varies from €77.62- €517.44 per month depending on the degree of disability and its impact. The benefit is payable from birth up to age 21. If a child over the age of 18 is employed the supplement may still be payable depending on the type of work.

Entitlement to the benefit is based on three criteria:

- i) The level of mental or physical disability
- ii) The degree of activity and participation of the individual
- iii) The impact on the child and their family.

Points are granted under each of the three headings (e.g. the greater the level of disability or care required, the higher the points) and the benefit is awarded (or not) depending on the point total. A child must score at least 6 points to receive a benefit. There are six different levels of payment. Those with 6-8 points get the lowest level while a child with over 20 points gets the highest. Over one-third (35%) of claimants are on the lowest rate of payment while only 9% are on the highest. The proportion of claimants generally declines as the level of points required increases.⁷

The Belgian social insurance system is operated through different social security funds (*caisses*). There is a significant variation in the level of awards in respect of disabled children depending on the fund with which their parents are insured. Research by the Belgian social security authorities has found that the funds which have a higher percentage of adult invalidity pensioners also have a higher percentage of disabled children, suggesting that there are socio-economic factors at play in determining the level of awards.

Assessment and adjudication of the disability payment

The person submits a claim (accompanied by a medical certification of the disability) to the social security authorities who arrange an examination by a doctor employed by the social security agency. This involves an interview with the parents and, generally, a physical examination of the child. The examination looks at each of the three criteria. First, points are awarded according to the percentage disability (0-6 points). Like France Belgium has a somewhat notional official scale which provides for the conversion of various disabilities into a standard percentage score. Second, the doctor considers the integration of the child in her environment and her autonomy (mobility / movement). This concerns the progress of the child, her

⁷ There are 25% on the second, level, 15% on the third, 11% on the fourth and 6% on the fifth level of payment.

lifestyle, and efforts to maintain daily contact. Four criteria are defined: education and special integration, communication, mobility and bodily needs. From 0-3 points are awarded under each heading. Finally, the doctor looks at the consequences of the disability for the child and family. Three areas are examined: treatment provided at home; movement for medical treatment; and adaptation to surroundings and habits. Up to 6 points are awarded under each heading. The points are then totalled and the appropriate level of benefit (if any) is calculated.

The doctor is required to submit his or her conclusions on the examination within 90 days of receipt of the application. The social security fund then decides if the person is entitled to the payment. If the parent is dissatisfied with the decision, a review may be requested which automatically involves a re-evaluation of the qualification criteria.

The doctor sets a review date for the child and a review is carried out by the social security agency at least 150 days before the expiry of the period of entitlement.

Canada

Context

Policy framework

As Canada is a federal state, responsibility for the provision of supports for people with disability is divided between the federal government and the provinces and territories. Canada does not have a national disability law. However, people with disabilities are protected against discrimination by the provisions of the Canadian Charter of Rights, the federal Human Rights Act and provincial equality and human rights legislation (e.g. the Ontario Human Rights Code). A national disability Act has been proposed but has not, as yet, been adopted.

Institutional arrangements

At a federal level, disability policy is the responsibility of the Department of Human Resources and Skills Development. Canada has established a federal Office for Disability Issues which is a focal point within the Government of Canada for key partners working to promote the full inclusion and participation of Canadians with disabilities in all aspects of society and community life. In general, the federal government is responsible for social insurance benefits and benefits paid through the tax system. In Canada, the child benefit system operates through the tax system and, therefore, the Canada Revenue Agency is responsible for the administration of benefits for children with disabilities. Provincial and territorial authorities are generally responsible for social assistance payments which vary significantly from one area to another. There are ten provinces and three territories.

Social services

Social services for people with disabilities are generally the responsibility of the province or territory in which they live. There is, therefore, significant variation in the level and structure of services provided from one area to another. In Ontario, the regional offices of the Ministry of Children and Youth Services provide a range of supports to children with disabilities including rehabilitation and respite care. The Ministry also provides a 'Special Services at Home' programme which helps families who are caring for a child with a developmental or physical disability.⁸ The programme helps families pay for special services in or outside the family home as long as the child is not receiving support from a residential programme. For example, the family can hire someone to help the child learn new skills and abilities, such as improving their communications skills and becoming more independent; and/or provide respite support to the family. The amount of money a family receives

⁸ <http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/specialservices/index.aspx>

depends on the type and amount of service the child needs, what other help is available in the community, and what kind of support the family is already receiving.

Health care

In Canada, health care is provided by provincial and territorial schemes. However, the federal Canada Health Act specifies the conditions and criteria with which the provincial and territorial health insurance programmes must conform in order to receive federal transfer payments. In Ontario, health services are provided through the Ontario Health Insurance Plan (OHIP). This programme includes the provision of financial assistance to Ontario residents with long-term physical disabilities to help them get equipment and supplies they need for independent living.

Cash payments for children with disabilities

The main payment for children with disabilities in Canada is the Canada Disability Benefit (CDB) introduced in 2003. This forms part of the Canada Child Tax Benefit (CCTB) package and, as such, it is a non-refundable tax credit which is administered by the Canada Revenue Agency (rather than by a social security body). It is intended to assist low- and modest-income families with the costs arising from the child's disability. The benefit is up to \$2,575 per year (\$214.58 per month) [€2050 per year and €170 per month]. It is paid as a monthly supplement to the CCTB. However, it is income tested and, unlike most other benefits considered in this report is targeted on those on lower incomes. The CDB amount is calculated according to base income, which is determined by the number of children for whom the CCTB is received.⁹ It is payable from 0-17 years of age. Recipients must be the primary caregivers of a child under age 18 who has a severe and prolonged impairment in mental or physical functions.

The CDB is a national (federal) scheme. As noted above, there are also provincial supports for people with disabilities which vary from area to area. In Ontario, for example, the Ontario Disability Support Program helps people with disabilities who are in financial need to pay for living expenses, such as food and housing through the provision of means-tested benefits and employment supports.

⁹ For example, a person with one child will receive the full CDB if their annual family income is less than \$42,707 [€33,584] while a person with 5 children will do so if the income is \$53,689 [€42,220]. A person with one child will receive no CDB where their income exceeds \$160,000 [€125,820] while a person with 5 children would continue to receive some CDB up to a family income of \$390,000 [€306,700].

The CDB generally is not linked to provincial or territorial social assistance schemes such as the Ontario Disability Support Program.

Assessment and adjudication of child disability benefit

In order to claim a child disability benefit, the tax payer must submit a Disability Tax Certificate.¹⁰ This is a form completed by a qualified doctor (or other medical professional for specific disabilities) which sets out the impairment and its impact on the claimant. It is, in fact, a general certificate which is also used for other tax-related disability benefits and is not specific to CDB. A decision is then made on the application by the Revenue authorities based on a review of the information contained in the certificate. If a determination cannot be made on the basis of this information, the file may be referred to the CRA's medical review team. It will be noted that, unlike all other payments considered in this report, entitlement to the benefit is based on impairment in functions rather than on an assessment of the additional care required.

In 2004, the Canadian Department of Finance carried out an evaluation of the Disability Tax Credit (DTC) generally (not specific to the CDB) (Department of Finance, 2004). This found that the DTC improved tax fairness for over 400,000 Canadians with severe and prolonged disabilities, as well as their families; and that the DTC was reaching its target population, i.e. Canadians with severe and prolonged disabilities.¹¹

More recently the Corporate Audit and Evaluation Branch of the CRA carried out an audit of the administration of the Disability Tax Credit (again not confined to the CDB).¹² The objective of the audit was to provide assurance on the effectiveness of the internal controls in place to ensure the objectives of the DTC program were being met. The audit found that, overall, the policies and procedures were in place and communicated to support fair and equitable determinations of DTC eligibility. It made a number of recommendations including strengthening controls relating to programme management; developing measures and indicators for quality to provide a more comprehensive performance reporting of the programme; existing performance measures for timeliness should be refined; and the quality review (QR) process needed to be strengthened.

¹⁰ <http://www.cra-arc.gc.ca/E/pbg/tf/t2201/README.html>

¹¹ The conclusion was based on the fact that estimates of the DTC recipient population based on Statistics Canada survey data were in the same range as the actual number of DTC recipients.

¹² <http://www.cra-arc.gc.ca/gncy/ntrnl/2011/dtcr2011-eng.html>

There do not appear to have been any external evaluations of how the system is working nor surveys of customer views.

Finland

Context

Policy framework

Finland's policies for disabled children have evolved over the past two decades. On the basis of the adoption by the United Nations of the *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* in 1993, Finland incorporated a provision on the equal treatment for persons with disabilities into the Constitution Act of Finland two years later in 1995. According to the Constitution Act no one shall be assigned a different status on the basis of their health or disability and the state and municipalities must work actively to implement the rights of disabled people. The principles of Finnish policy concerning people with disabilities are the rights to: equality, participation, and positive special treatment.

In support of these principles policies have been introduced to promote the independent living, equal opportunities and participation in society of disabled people through eliminating physical, attitudinal and communication barriers and including disabled people in the policy making processes at national and municipal levels. Hence Finland's approach to disability is within the context of the 'social model' of disability which sees the norms, standards and organisation of society presenting 'disabling barriers' that prevent disabled people enjoying equality of opportunity with non-disabled people. In this context the focus of disability policy in Finland has shifted from services and rehabilitation to removing barriers and obstacles to the equal participation of disabled people in all aspects of Finnish society. Specifically, policy has focused on improving accessibility of housing, the built environment and public spaces, transport, communication and information and participation in decision making. Corresponding to signing the *United Nations Convention on the Rights of Persons with Disabilities, 2006*, Finland set out new policies and activities in the *Government Report on Disability Policy, 2006*. The most recent developments to disability policy are set out in *A Strong Basis for Inclusion and Equality Finland's Disability Policy Programme VAMPO 2010–2015*.

Institutional arrangements

Finland's disability policy is based on the Nordic welfare model which aims to provide all residents with the services they need, regardless of their financial status. Provision is mainly tax financed and publicly provided. Responsibility for services for disabled children is divided between central and local government. The Ministry of Social Affairs and Health is responsible for strategy, planning, legislation, guidance and monitoring of social welfare and health care services. The municipalities are responsible for delivering social welfare and health care services. Legislation obliges the municipalities to provide the necessary social and health services for their inhabitants including disabled children. Provincial State Offices oversee provision at

regional level. The Social Insurance Institution, KELA, is responsible for providing vocational education for disabled people, their income security and the medical rehabilitation of severely disabled people. Disabled people and their organisations make an input to policy through the National Council on Disability which is linked to the Ministry of Social Affairs and Health; while at local level, administration and NGOs liaise through municipal councils.

Social services

Municipalities are required by law to provide seriously disabled people with services and financial support necessary for independent living. Municipalities receive state subsidies, and may deliver services directly themselves or augment provision by buying in some services from the private sector and NGOs. The medical, educational and social rehabilitation of children with a disability and support for their families is started immediately the impairment is detected and the relevant authorities draw up, with the parents, a service plan to identify the services and benefits needed by the child and its family. Services may include: rehabilitation, adaptation and rehabilitation guidance, home renovations and assistive aids, a personal assistant, family care or institutional care, support for informal care, financial support, and interpretation services. A contact person is appointed to act as a link between the family and the different authorities providing the various services.

Health care

Hospitals and healthcare centres have statutory responsibility for arranging rehabilitation for disabled children. Children with severe disabilities whom KELA has awarded disability allowance at the middle or the highest rate are entitled to medical rehabilitation services specifically for persons with severe disabilities.¹³ Rehabilitation may include individual therapy or group rehabilitation or training in adapting to disability. 'Adaptation training' for children with disabilities and their families is arranged by municipalities, KELA and disability organisations. Parents of a child participating in rehabilitation are eligible for a 'Rehabilitation Allowance'. Assistive aids are available from health centres or by referral from the assistive device units of health care districts.

Cash payments for children with disabilities

Parents of disabled children can apply for various financial benefits paid by KELA. The most important of these is the disability allowance for persons under 16 years of age. This allowance is payable for children having an illness or disability that creates a need for care that lasts at least 6 months. The objective of the payment is to compensate for the additional strain caused by sickness or disability. The allowance

¹³ These are children who require daily (middle rate) or round-the-clock care (higher rate).

is payable from 0-15 years. The benefit is graded into three classes depending on the degree of strain on the family: basic rate (€89.18 per month); middle rate (€208.09 per month); and highest rate (€403.50 per month). Overall, 52% of claimants are on the basic rate; 41% at the middle rate and 7% on the high rate. However, in 2011, 81% of current awards were at the basic rate with 15% at the middle rate and only 4% at the high rate.

Families may use the disability allowance as they wish. There are several studies about families with sick or disabled children. However, these studies do not focus on disability allowance for persons under 16 years of age and most of these studies are available only in Finnish.

In addition, a special care allowance for children under 16 is available if a parent or guardian has to temporarily stop working in order to look after their child, who is under the age of 16. The 'Special care allowance' provides compensation for loss of income during periods in which a person is completely unable to work, operate a business or study full-time because of the sudden onset or exacerbation of their child's illness. To qualify for the special care allowance, a person must:

- participate in the treatment or rehabilitation of their child, who is under 7 years old, in a hospital, outpatient clinic or a rehabilitation or adaptation training course, or
- participate in the hospital or outpatient treatment or rehabilitation of their child, who is between 7 and 15 years of age and severely ill, or
- Look after their child, who is under 16 and severely ill at home as part of a hospital or outpatient treatment plan.

Local authorities may pay an informal care allowance for family members caring for a sick or disabled child. Informal care allowance is an official, statutory social service, financed by local authorities, supported by central government subsidies. It provides cash for carers and services to support the care of an elderly, disabled or sick person in their home with the aid of a relative or another person who is close to the person who is being cared for. Informal care allowance may be granted on the basis of both temporary and long-term need for care. Entitlement is based on need and not on a test of means. An agreement on necessary informal care is concluded between the informal carer and the local authority, and a plan of care and services is appended to the agreement. The minimum care allowance defined by law in 2011 was €353.62 per month. If the informal carer is temporarily prevented from working during a difficult transitional period in the care arrangements, the minimum allowance is increased to €707.24 per month, subject to certain income-related conditions. The law sets the basic framework for calculation of the allowance and within those

parameters the municipalities have discretion to decide the specific levels. Municipal budgets may be insufficient to meet demand.

Assessment and adjudication of disability allowance

The eligibility criterion is an illness or injury that creates a need for care and rehabilitation that lasts at least six months and imposes particular strain and requires a greater commitment than the care of non-disabled children of the same age.

A medical diagnosis provides the evidence on the medical condition. The degree of care required forms the basis of the assessment. Thus the amount of Disability Allowance payable depends on the strain that the illness or disability imposes on the family and the level of commitment it requires. The Disability Allowance is awarded at an increased rate if the daily care of the child is demanding and time-consuming on a daily basis. The third, and highest, rate of disability allowance is for children who need around-the-clock care. As part of the assessment KELA evaluates how much extra time is needed when taking care of the child. This includes the need for transportation (for example, to and from rehabilitation), taking care of the child's diet and/or medication, using sign language or some other way of communication etc. KELA does not use specific percentages or hours in the evaluation when determining the amount of care that the child needs. Both the Disability Benefits Act and KELA's own guidance refer to the need for 'weekly', 'daily' and 'round the clock' care. KELA guidelines do not define these words any more precisely (with any percentages or hour limits). When considering the overall evaluation of the child's individual circumstances KELA officials believe the broad definitions (weekly, daily and round the clock) give more room to do their evaluation.

Certain conditions are considered to be relatively uniform in terms of the amount of care and assistance they demand, the strain they impose and the level of commitment they require. These diseases and the special needs associated with them are defined in the administrative guidelines applied by KELA. Such diseases include heart defects, vision and hearing disabilities, cerebral palsy, epilepsy and mental illnesses. However, while the guidelines include examples on how these illnesses or disabilities should be evaluated the decision is always based on the overall evaluation of the child's situation and KELA officials believe therefore that it's very important to take into consideration the child's individual circumstances.

A medical certificate and a doctor's statement, form C, should be enclosed with the application form B. The medical certificate/statement gives the medical side while the application form gives information on the situation within the family and care needs. There are questions in application form B that ask about the family's concrete circumstances. These questions concern the child's day care (how it is organised), school (what kind of help is needed during class etc.) and rehabilitation (what kind of rehabilitation, how often etc.). There are also questions about the

actions, measures, inconvenience and extra work that are needed when taking care of the sick or disabled child. The application form allows the claimant plenty of space to give precise and detailed answers on how much time the different measures or actions take.

Assessments are made by KELA's officials. Some of them have medical qualifications (e.g. nurse). KELA also has medical doctors who can help in making the assessment. KELA considers that the application form B should give them the necessary information about the situation at home and the medical certificate C and other medical evidence provides the medical context. The personnel in KELA compare and combine the information from both forms.¹⁴ In 2011, 80% of applications were successful as were 86% of applications for an extension of an award. Appeals can be made to the social security appeal board and in 2011, the decision was altered in 25% of all cases.

¹⁴ The Finnish version of the application form can be found at:
<http://www.kela.fi/in/internet/suomi.nsf/NET/211108143639AK?OpenDocument>

France

Context

Policy framework

The main policies concerning disabled people in France are set out in the Loi no. 2005-102 « pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées ». (Law for equal rights and opportunities, participation and citizenship of disabled persons of 2005). The law set out a new direction for disability policy in France and amended many existing provisions. The 2005 Act emphasizes the rights of people with disabilities. To enforce the law over 100 implementation decrees, numerous guidelines and regulations have been issued following its adoption.

The general principle of the 2005 Act refers to the freedom of choice of the disabled person and his or her participation in all decisions concerning him or her. It is based on two pillars: accessibility and compensation. Accessibility is understood in a global sense, i.e. to provide environmental, social, economic and cultural adaptations and accommodations to give people with disabilities access to mainstream education, labour market, housing, culture, leisure. The principle of accessibility for all, whatever the disability, was re-affirmed, but with new definitions of accessibility criteria and time limits to comply with the law. The second major pillar refers to a compensation scheme that includes the innovation of an individual budget and the development of support services in the community.

In September 2012, the new French government issued a directive to all ministries insisting that any new laws must take into account their impact on those with disabilities.

Institutional arrangements

Disability policy overall is the responsibility of the Ministry of Social Affairs and Health (Ministère des Affaires Sociales et de la Santé). One of the important reforms in the 2005 Disability Act was to reform the structures for the delivery of disability services at local level. A 'Maison départementale des personnes handicapées' (MDPH) (Départemental Disability Centre) was established in each 'département' under the responsibility of the Conseil General of the département (general council). These institutions act as a single contact point for persons with disabilities in each département. A 'Commission des droits et de l'autonomie des personnes handicapées' (CDAPH) is attached to each Maison and is responsible for assessing the needs and eligibility of persons with disabilities for a range of disability services including social security, social services and education. Social security benefits for persons with disabilities are provided by the general social security authorities (the Caisse nationale des allocations Familiales or National Office for Family Allocations).

Social services

The MDPH is intended to ensure 'the necessary assistance in the formulation of the person's life plan, the necessary assistance in the implementation of decisions taken by the CDAPH, support and mediation that implementation may require.' This support includes the assessment of disability and compensation requirements defined by the life plan. This work aims to develop a personalised compensation plan (PPC). The development and implementation of the PPC depends on the MDPH which ensures the processing of applications concerning the allocation of benefits, invalidity cards, school counselling, medico-social or professional support, etc. and the implementation of the decisions of the CDAPH.

One important reform in the area of social services has been the introduction of a new scheme of 'prestation de compensation du handicap' (PCH). This is a personalised cash payment intended to provide financial support linked to the loss of autonomy of disabled people. It comprises five separate elements: personal assistance, technical assistance, housing and transport, exceptional or specific expenses, and 'animal assistance' (e.g. where a person needs the assistance of a guide dog). It applies to both adults and children (since 2008). Unlike the existing social security payment (see below) which is funded as part of the social security system, the PCH is funded by the départements. It appears to be intended that, over time, the PCH will replace the existing social security payment (AEEH). The average monthly payment of PCH is €800 (for all age groups) but there is considerable variation depending on the elements supported.

Health care

The French health care system is one of universal health care largely financed by government national health insurance. The 2005 Disability Act guarantees equal access to basic rights which includes health care. However, despite the generally high quality of French health care, it is reported that 'Health care provision remains unsuitable for disabled children: screening often belated, access to health care far more difficult for them than for other children.' (ANED, 2009).

Cash payments for children with disabilities

In France, the main payment for disabled children is the allocation d'éducation de l'enfant handicapé (AEEH) or education allowance for disabled children. This benefit has existed since the 1970s but was renamed as part of the 2005 reforms. It is a social security benefit funded by the family branch of the French social security system. The objective of the payment is to assist families with the additional costs of caring for a disabled child. It is payable in respect of children from birth up to the age of 19. However, the number of applications from younger children is relatively low and the average age of a new claimant is seven years and five months. The AEEH will

no longer be payable if the child is working and earns more than 55% of the minimum wage (SMIC).

The amount of the benefit varies greatly from €127.68-€1,210.11 per month depending on related costs and degree of care required. In order to establish entitlement to the basic level of payment, a child must have 80% disability (according to a set tariff) or between 50-79% if s/he goes to a special school or has special needs.¹⁵ The payment is not means-tested nor is it subject to income tax.

The basic amount of the AEEH may be increased if the child imposes particularly heavy financial constraints on the family. This is measured by

- i) The costs arising from the disability; and
- ii) Whether the parent(s) have to give up work (in full or in part) to care for the child.

There are a total of six different levels of supplement depending on the additional need for care.¹⁶ The first supplement is for children whose care gives rise to extra costs only. Supplements 2-4 are for children who require the additional care of a person part-time (whether a parent or other person). Supplements 5-6 are for children requiring full-time care. Data indicate that over half of all recipients of the AEEH (56%) receive only the basic payment (of €127.68 per month) while only 3% receive the highest level of payment (CAF, 2009). The most commonly paid supplements are level 2 - €387.03 per month (19% of all recipients), level 3 - €494.76 (10%) and level 4 - €696.53 (8%). In 2010, the minimum level of the AEEH constituted 10.6% of the French minimum wage (SMIC) whereas the maximum was almost equal to the minimum wage (98.6%).

There do not appear to have been detailed evaluations of the AEEH. However, a report for the École nationale d'administration stated that the amount of the AEEH remained modest and could only cover a small part of the need for care (up to three hours per day) (ENA, 2006).

As noted above, it appears that it was envisaged that the PCH would eventually replace the AEEH. However, at present, the AEEH remains in place and persons can opt for one or the other.¹⁷ To date the number of children opting for the PCH

¹⁵ French law provides for a somewhat notional system for converting specific disabilities into a standardised percentage figure.

¹⁶ There is also a separate supplement for lone parents.

¹⁷ The basic rate of AEEH is payable together with PCH but not the supplements.

remains relatively modest compared to the numbers on the AEEH but the number of new claims is growing. It appears that the PCH may be more attractive for those with relatively high levels of care needs. It has been estimated by the social security authorities that in 2010, persons opting for the PCH reduced the AEEH budget by about €50 million in that year.

There are also other benefits available for disabled children such as the 'invalidity card' (carte d'invalidité) which gives a right to a range of benefits, in particular transport. However, these are not directly linked to the AEEH.

Assessment and adjudication of AEEH

Applications for the AEEH are considered by the Commission des droits et de l'autonomie des personnes handicapées (CDAPH). This is an agency which is established at the local Maison départementale des personnes handicapées (MDPH). It includes representatives of the département, the public services and social security agencies, trade unions, parents associations, and representatives of disabled people and their families.

A multi-disciplinary team from the MDPH carries out an assessment of the child's disability and need for care based on the medical certification and application submitted. The team considers the child's educational needs and also the need for technical aids, housing and social supports. The teams include persons with medical or paramedical, psychology, social work, education, employment and training expertise. When complete the assessment is sent to the CDAPH which decides whether the child satisfies the requirement for the basic payment and, if relevant, which level of supplement is payable. About 92% of applications are recorded as being granted and the average time from receipt of application to a decision is two and a half months. If a decision is not made within four months, the application is deemed to be refused. The CDAPH sets a period from the award which can vary from 1 to 5 years. However, the parents can apply for a review if the child's condition worsens in the period.

If a person is dissatisfied with the decision, s/he can appeal to a specialist incapacity tribunal (tribunal du contentieux de l'incapacité) which also deals with other disability appeals. The precise number of appeals from decisions concerning the AEEH is not known but overall there is a very low appeal rate with only 0.5% of all decisions given by the CDAPH being appealed (including those concerning AEEH, PCH and other supports).

Netherlands

Context

Policy framework

The policy of the Dutch government towards people with a physical or mental impairment is based on the social model of disability and is intended to remove the barriers that prevent disabled people functioning independently within society. Discrimination on any grounds is prohibited in the Netherlands under Article 1 of the Constitution. The Municipal Anti Discrimination Services Act entered into force in 2009. The Act ensures that everyone has the opportunity to report (alleged) discrimination in their own locality. In addition, everyone is entitled to receive assistance and advice from an anti discrimination service (ADV). The Act on Equal Treatment of Disabled and Chronically Ill People came into effect on 1 December 2003. The Act forbids discrimination against disabled people in prescribed areas. The Act is seen by some as marking a change from 'care' for disabled people to establishing rights. The majority of care facilities and services for disabled people – including the TOG Care allowance for disabled children - are funded through the Exceptional Medical Expenses Act (AWBZ), which is public insurance providing entitlement to long-term health and social care.

Institutional arrangements

The Ministry of Health, Welfare and Sport funds the majority of care facilities for disabled children through public health insurance. Educational support is funded and provided through the Ministry of Education, Culture and Science. The Ministry of Health, Welfare and Sport coordinates policies on disability with four other ministries: the Ministry of Education, Culture and Science; the Ministry of Social Affairs and Employment; the Ministry of Transport, Public Works and Water Management; and the Ministry of Public Housing, Physical Planning and the Environment in the Interdepartmental Committee for Coherence and Coordination in Disability Policies and/or the Chronically Ill. The Committee is a consultative body for the alignment, development, and coordination of the central government's disability policies. The Domiciliary Care Institutions (there are about 142 of these in the Netherlands) provide additional care and assistance to people with a physical or mental disability who are living independently or with their parents or carers. The Sociale Verzekeringsbank (SVB) is the organization that implements national insurance schemes in the Netherlands. The SVB implements social insurance schemes and regulations for several ministries, including the 'TOG care allowance scheme for disabled children living at home' for the Ministry of Social Affairs and Employment. The Ministry of Social Affairs and Employment makes policy and the SVB is responsible for implementing the TOG Care allowance and is answerable to the Minister. There is a further division of responsibility between the SVB which administers the public insurance fund AWBZ which provides the TOG care allowance

and the bodies responsible for assessing the need for care (Care Assessment Centre (CIZ) and The Youth Care Agency (BJZ)); and the care providers (this is discussed further below).

Social services

The Social Support Act (WMO) was introduced in 2007 to promote and manage the integration of people with limitations in society. The Act makes municipalities responsible for home care, supporting and activating care, as well as the regulations for transport, client support and various subsidies. The municipalities are responsible for financing and contracting of all WMO activities and for quality of care. Care providers negotiate contracts with the municipality. Under the Act, the municipalities must establish a central information point to provide disabled people and their families with assistance in applying for personal care, making adjustments to their home, accessing mobility devices, home help etc.

When a child of between the age of 0 and 4 is diagnosed with a disability the parents may contact their local MEE Nederland office (a national programme funded by the Health Care Insurance Board from AWBZ funds) which will inform them of the different service options that are available to them in terms of adaptations, transport etc. and assist them to access support, develop personal care plans and apply for assistance from AWBZ or the WMO. If a disabled child requires long term care their parents or guardian will go to the Centre for Needs Assessment (CIZ) to be assessed to see if they are eligible for Long Term Care Insurance (AWBZ). This assessment is means tested and the person's contributions to their insurance, their care needs and their care budgets are based on this assessment. If a person is assessed as being eligible for this type of insurance, they can choose between receiving care in kind and having a personal care budget.

If a person chooses care in kind they have some choice as to which care organisation delivers their care. Recipients go to their regional care office which is run by a health insurance company which is responsible for organising and purchasing care for people with disabilities using Long Term Care Insurance (AWBZ). There are 32 regional care offices in the Netherlands. The health insurers have a list of long term care providers that they recommend to a service user.

The personal care budget (PGB) is a form of direct payment for disabled people. People who have Long Term Care Insurance (AWBZ) or Social Supports Insurance (WMO) can choose to use a personal care budget. A disabled person who chooses a personal care budget receives 75% of what their care in kind would cost. They can purchase the type of care they wish including institutional care, social services in their home or use their personal care budget to pay family/ friends who care for them. This is designed to make it easier for disabled people to continue to live at home and in their communities for as long as possible. The PGB was introduced in

part to cover limitations in the traditional healthcare system, but also to offer service users more choice and control over their care.¹⁸ There was also a belief that handing control of budgets to the user would help to reduce costs through encouraging competition and innovation in service provision.¹⁹

The PGB enables a budget holder to choose and pay for the carer(s) she or he wants. The budget is paid directly into the budget holder's bank account, either monthly, quarterly, twice a year, or yearly, depending on the amount of the entitlement. Budget holders must account for how they spent the money – annually if the amount is less than €5,000 a year, twice a year if more. Up to €1,250 (1.5%) of the annual budget does not need to be accounted for. Anything left over from the budget must be repaid. Around 10–15% of budget holders repay some of their annual allowance.²⁰ The Centre for Needs Assessment (CIZ)'s care liaison office checks that holders of a personal care budget use the money appropriately. The fastest growing group of budget holders are people under 18, who comprise around 45 per cent of the total.

The total national budget for Personal Care Budgets is capped and demand exceeds supply. It should be noted that the number of children (under 18) supported by the PGB (about 56,000) far exceeds the numbers in receipt of the TOG and the annual payment (€17,000 on average) is far higher. Therefore, the PGB budget in respect of children (close to €1 billion) massively exceeds that of the TOG.

Health care

In 2006, major health care reforms took place following the introduction of the Health Insurance Law (ZVW) which replaced the two tiered system of social and voluntary private health insurance with one single mandatory private scheme (ZVW) to provide cover for a range of services from medical and dental care to transport costs for people in wheelchairs. Since 2006, the provision of healthcare has become more decentralised in the hands of the private independent health insurers.

Cash payments for children with disabilities

There are two types of public long-term care insurance for disabled children: the Exceptional Medical Expenses Insurance Act (AWBZ) introduced in 2006 and the Social Support Insurance Act (WMO) in 2007. If a person with a disability cannot

¹⁸ Ibid.

¹⁹ Ibid.

²⁰ White, C. (2011) Improvement in practice: The personal touch. The Dutch experience of personal health budgets, The Health Foundation.

afford any public long-term care insurance the Dutch government provides insurance.

The TOG care allowance forms part of the AWBZ. It is a contribution towards expenses of raising and caring for children who are disabled or severely ill and who live at home and is payable to children aged from 3 to 17. The rate of payment is € 215.80 per quarter. In 2011, 30,057 children received the TOG care allowance. This represented 1.02 % of the 2,941,900 children aged between 3-17 years of age. The total expenditure on the TOG care allowance in 2011 was € 22,400,000. This represented 0.03% of total social security payments (€ 77 billion exclusive of care; € 139 billion inclusive of care); and 0.0037% of GDP (€ 602 billion, 2011).

The TOG criteria were reformed in 2010. Prior to the change the TOG had its own medical assessment under which SVB tested whether the child was 'significantly more dependent on regular care or attention than a healthy child of the same age'. The new criteria were aimed at removing the need for a double medical assessment (for TOG and AWBZ care); and to reduce the number of children in receipt of TOG. The impact has been that before the change in 2010 there were 65,500 children in receipt of TOG; and by the end of 2011 this had reduced by over 50% to 30,057 children in receipt of TOG.

The TOG may be payable with the personal budget (PGB) described above. In addition, a person who has been in receipt of a TOG care allowance for 12 months or more may also be able to get '*Extra financial support for single-income households*'. The extra financial support is means-tested and provides for the whole family, not for each child separately; therefore, it makes no difference whether a parent looks after one or more children.

Assessment and adjudication of TOG payment

A child is considered to be disabled for the purposes of the TOG scheme if he or she has a physical or mental condition which causes restrictions, and results in the child being substantially more dependent on care, assistance and supervision than a non-disabled child of the same age. A parent or the responsible adult must submit a claim form accompanied by a report or a statement by the doctor who is treating the child and an AWBZ assessment under the National Act on Exceptional Medical Expenses (AWBZ) and/or a ZG certificate (for a sensory impairment). An AWBZ indication (or a ZG certificate) establishes how much more help or care a child needs than a child without an illness or disability. An AWBZ indication or a ZG certificate will only be given for children who need extensive care because of an illness or disability. AWBZ assessments are carried out by the Care Assessment Centre (CIZ) and the Youth Care Agency (BJZ). The Youth Care Agency (BJZ) carries out assessments for children with psychological problems, and the Care Assessment Centre (CIZ) carries out assessments in all other cases. ZG certificates for children with sensory impairment

are issued by a registered specialist care provider. The CIZ - which is independent from the health insurance and health care providers and has been in existence since 2005 - assesses whether a disabled child is entitled to AWBZ care on the basis of objective national criteria, so that the assessment is the same everywhere in the country. These criteria are derived from Ministry of Health guidelines. The CIZ has 1,700 employees some of whom are medically qualified.

The AWBZ assessment of care needs is categorized into standard 'functions' such as: personal care; nursing; assistance; and institutional care. Each function is classified according to intensity, establishing an average number of hours, days or sessions of care that a child needs per week. Sessions consist of 4 hours, and days of 24 hours. To qualify for a TOG care allowance, a child needs an AWBZ and/or a ZG certificate indication averaging 10 hours of care or more per week.

For example, a child has a class 4 *personal care* indication. Class 4 is 7 to 9.9 hours of care. The average of class 4 is 8.45 hours a week. The child also has a class 2 indication for *nursing*. Class 2 is 2 to 3.9 hours of care. The average of class 2 is 2.95 hours per week. The amount of personal care and the amount of nursing are added together. Thus the total amount of care the child needs in this example is, on average, 8.45 hours of personal care + 2.95 hours of nursing care = 11.4 hours of total care per week. This means that the AWBZ indication averages more than the 10 hours a week threshold for receipt of the TOG Allowance. If a child has an indication for *institutional care* of 1 day (and night) a week this counts as 24 hours, which means that the AWBZ indication averages more than 10 hours a week.

The assessment for a ZG certificate, which establishes how much assistance or care a child with a sensory impairment needs, follows the same principles as that for the AWBZ indication. If a child has both an AWBZ indication and an ZG certificate for a sensory impairment both will be taken into account in calculating qualifying hours for a TOG care allowance so that a child is entitled if the ZG certificate and the AWBZ indication together represent an average of at least 10 hours of care per week. The AWBZ indication applies for a period of from 3 months to a maximum of 5 years.

About 80% of initial applications are successful. Only a small number of cases are appealed to the social security courts. However, it is possible to ask the SVB to review its decision and in about half of the cases involved, the decision was reversed.

United Kingdom

Context

Policy framework

The policy framework for disabled children in the United Kingdom (UK) has evolved over 40 years. The Disability Discrimination Act 1995 introduced measures aimed at ending discrimination against disabled people including access to goods, facilities and services. The Disability Discrimination Act was seen by many as signalling a fundamental shift away from a medical model of disability towards a social model. The Disability Equality Duty, introduced by the Disability Discrimination Act 2005, required public sector organisations (including schools and hospitals, local and central government) to be proactive in ensuring that disabled people are treated fairly and are included in all aspects of policy development from the outset. The Equality Act 2010 simplified, extended and clarified the Disability Discrimination Act.

In addition to legislation, guidance sets standards for service provision for disabled children. The National Service Framework for Children, Young People and Maternity Services 2004 set standards in children's health and social services to be implemented over ten years to 2014. There are specific standards to address the requirements of children and young people and their families who are disabled and/or have complex health needs (see below). National level performance indicators and targets have encouraged a focus on disabled children. The legislation, guidance and performance targets and indicators have been backed up by improved data on disabled children on which to base service planning, commissioning and provision at national and local level. 'Aiming High for Disabled Children (AHDC)', launched in May 2007 set out a strategy for disabled children's services. Its stated aim was 'to improve service provision across the board for disabled children and their families, enhancing equality and opportunity for them'.

The current government, elected in 2010, has set out its policies for disabled children most recently on 17 September 2012 in 'Fulfilling Potential – Next Steps'. Key elements of which are:

- A new cross sector disability action alliance involving disabled people, their organisations, and others from the public, private and voluntary and community sectors will work together to identify and deliver the change needed to bring about equality of opportunity for disabled people
- Public service reform which will support disabled people's independence and participation

- A new partnership approach which will see disabled people having much more influence in the design and delivery of services, so they are better able to challenge where things are not delivering the outcomes they need.

Institutional arrangements

These policies and programmes are delivered by several government departments including in particular the Department for Education (responsible for education and children's services), the Department of Health, the Department for Work and Pensions (DWP), the Office for Disability Issues (which is housed in the Department for Work and Pensions but works across all areas of government policy) and the Government Equalities Office which leads on discrimination issues and legislation. The Disability and Carers Service is part of the Department for Work and Pensions. It provides financial support for people claiming disability benefits and their carers, including Disability Living Allowance and Carer's Allowance.

Social services

Social services departments have a general duty under Section 17 (10) of the Children Act 1989 to safeguard and promote the interests of 'children in need'. The law recognises disabled children as being in need. A child in need is entitled to an assessment from the social services department. This assessment sets out the services that are considered necessary. Duties of social services to disabled children and their families include: providing a social worker service; maintaining a register of disabled children; providing information about services which may be available; assessing the needs of disabled children and their carers; and providing a range of services to meet these needs.

The Children Act 1989 also sets out a range of specific support services which should be available. This includes the right to permanent or temporary residential accommodation, if appropriate, which forms the legal basis for residential short breaks. Other services listed in the Children Act include: occupational, social, cultural or recreational activities; home help; assistance to enable the child and family to have a holiday; advice, guidance or counselling; and travel assistance. The Children Act 2004 introduced children's trusts which were at the heart of the government's Children's Plan. Children's trusts aimed to promote coordination of services for children and families in local areas. The Children Act 2004 also introduced a 'Common Assessment Framework' (CAF).

Social services have limited financial resources and use 'eligibility criteria' to prioritise need. The criteria differ from one authority to another which means that people with similar circumstances may not get the same support in different authorities and if someone moves from one authority to another they may not qualify for the same support as they received previously.

Direct payments are cash payments made in lieu of social service provision. They can be made to people who have parental responsibility for disabled children, and to carers. The Health and Social Care Act 2001 introduced a requirement that families, who are eligible for social care services, including families with disabled children, must be offered the option of direct payments. Individual budgets build on some of the features of direct payments. While the largest potential source of income is the Social Care budget, individual budgets aim to provide a more joined-up package of support by including several other income streams in addition to social care services.

Health care

Healthcare for disabled children in the UK is provided by the National Health Service (NHS). The National Service Framework for Children, Young People and Maternity Services 2004 provides specific standards for the care and treatment of disabled children. Standard 8 of the Framework provides for 'Disabled children and young people and those with complex health needs', and requires that 'Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.' While Standard 9 provides for 'The mental health and psychological well-being of children and young people' and requires that 'All children and young people, from birth to their eighteenth birthday, who have mental health problems and disorders have access to timely, integrated, high quality multidisciplinary mental health services to ensure effective assessment, treatment and support, for them, and their families.'

Cash payments for children with disabilities

The main benefits for disabled children and their families are Disability Living Allowance, which was introduced in April 1992, designed to help people with the extra costs of meeting their personal care and/or mobility needs; and Carer's Allowance, intended for people who provide regular and substantial care to a severely disabled person (see below). In the context to major reforms to welfare the Government plans to replace Disability Living Allowance with a new cash benefit, called Personal Independence Payment (PIP) from 2013 although not initially for disabled children (this is discussed further below).

DLA is intended to help meet any extra costs of being disabled. It includes both 'care' and 'mobility' components. The care component is payable from the age of three months to the age of 16 years while the mobility component is payable from the age of three years to age 16. The criteria for the care component include requiring 'substantially more care from another person than children of their age would normally require'. The rates of DLA are £20.55 (low) - £51.85 (middle) - £77.45 (high) per week (care) [€25.70-64.90-96.90] and £20.55 (low) - £54.05 (high) per week (mobility) [€25.70-67.60]. The level of award depends of the level of care required by

the child (or the restrictions on the child's mobility in the case of the mobility component).²¹ A disabled child may be awarded either the care or mobility component or both at any of the possible different combinations of rates. One third of all children on DLA get the middle care and lower mobility award (the largest single grouping). 12.5% of children receive the higher rate of both the mobility and care components (the maximum), while 5.2% receive a lower award (care or mobility) only (the minimum).

Carer's Allowance is intended for people who provide regular and substantial care to a severely disabled person. Carer's Allowance is a non-contributory benefit paid to people providing care for 35 hours or more per week to individuals who are receiving Disability Living Allowance (at the middle or highest rate for personal care) (or Attendance Allowance (AA)/Constant Attendance Allowance at or above the normal maximum rate with an Industrial or Injuries Disablement Benefit or Constant Attendance Allowance at the basic (full day) rate with a War Disablement Pension). Carer's Allowance is not payable to full time students and is means-tested (currently it is not payable to a carer who is earning more than £100 [€125] after various deductions have been taken into account). The rate of Carer's Allowance in 2012 is £58.45 per week [€73.10]. Payment of Carer's Allowance is taken into account in full in the calculation of income-related benefits and Pension Credit. Receipt of (or an underlying entitlement to) Carer's Allowance qualifies for the carer premium in Income Support and income-based Jobseeker's Allowance, (currently worth up to £32.60 per week [€40.80]) and may impact of Housing Benefit and Council Tax entitlement.

Use of disability living allowance (DLA)

Studies show that there are additional costs associated with disability, that people value and appreciate DLA and AA, and that people say they would lead different lives (usually impoverished in some way) without it (Corden et al., 2010). This research showed that parents of child recipients of DLA spent money on the particular equipment or activities that would help and on treatment and tuition. Some parents had heavy expenditure on heating, electricity, transport and costs of maintaining or replacing appropriate clothes and shoes. Expenses spread across other family members, and into all areas of family life. Having DLA helped them pay for such items and services. Parents of child recipients who were living on low incomes said that without DLA their children's lives would be adversely affected, for example, spending less on items needed for their disabled child, such as extra lessons. However, the more generally reported effect would be reduction in living standards for the whole family. However, the question arises as to whether it is possible to put

²¹ See the DWP, Decision Makers Guide for the details of the qualification criteria.

a figure on the difference that DLA makes to people's lives. Berthoud suggests two possible ways for measuring impact of DLA - 'cross sectional comparisons, controlling for disability characteristics' and 'before and after' study of people before they make a claim for DLA and sometime after a successful claim (Berthoud, 2009). However, so far this work has not been done.

Assessment and adjudication of disability living allowance (DLA)

While DLA is intended to contribute towards extra costs arising from disability, measuring each individual's expenditure is considered to be administratively complex and expensive. Entitlement and award levels are, therefore, based on proxies – care and mobility – as research at the time when DLA was introduced showed that these were the greatest sources of extra costs (Department for Work and Pensions, 2012). The decision about whether to award benefit is made on the basis of the severity of an individual's care and mobility needs as a proxy for their extra costs.

The process is that a parent submits an initial claim on paper or on-line.²² The parent makes an assessment of the child's care needs and mobility difficulties on the application form. The form is very lengthy (43 pages) and requests detailed information about the impact that their child's impairment or health condition has on their ability to manage their care themselves and/or get around. Supporting evidence may be submitted with the application. This can be medical reports, speech and language assessments, psychological reports, and/or a statement of special educational needs. A DWP Decision Maker will then assess the claim and issue a decision on it. Decision Makers are not medically qualified and will rely on medical information supplied with the claim, plus DWP guidance. If the Decision Maker is unclear about how the child's condition affects their care needs and mobility, they may write to the child's doctor (GP) or hospital consultant or they may arrange for a DWP approved doctor to visit to examine the child and prepare a medical report on how the impairment affects functioning/daily living/mobility. At present around half of all DWP award decisions (all age groups) are made without any additional medical evidence and a medical examination is not usually required. Over 90% of those applying for DLA receive an award. A claimant has one month following a decision to ask for it to be reconsidered or to make an appeal.

DWP has contracted Atos Healthcare to provide medical advice to assist Decision Makers in reaching a decision regarding entitlement to Disability Living Allowance (and other disability benefits). Atos Healthcare uses a computer programme, LiMA (Logic Integrated Medical Assessment), during the medical assessment. This web-

²² www.dwp.gov.uk/advisers/claimforms/dla1a_child.pdf

based system was introduced by Atos 'to improve legibility, consistency and accuracy of the medical reports.' Disability support groups reported to the Parliamentary Work and Pensions Committee on Decision making and appeals in the benefits system that in their opinion DWP Decision Makers rely too heavily on the conclusions of the Atos healthcare medical assessment and claimed that not enough attention was given to claimants' own statements, supporting evidence and medical history (Work and Pensions Committee, 2010). The Parliamentary Committee concluded:

We note widespread concerns that decision makers appear to give excessive weight to the conclusions of DWP medical assessments over other evidence claimants may provide. If a claimant is able to provide statements from specialists, who have regular contact with them, this evidence should be given due consideration.

The Committee recommended that DWP should 'take action to improve decision makers' training, address inconsistencies in decision making, set minimum standards for the process of reconsidering decisions, increase the proportion of decisions that are pre-checked, make more effective use of personal communication with claimants, and improve the way in which decision making standards are monitored.'

The Committee noted that the quality of decision making depends in large part on the quality of the information provided to the decision maker and that 'the claim forms for DLA are notoriously complex and many claimants find them confusing'. The DWP has taken steps to improve and shorten application forms and plans to move away from generic claim packs over time to forms more focussed on the specific needs of particular claimants.

A National Audit Office (NAO, 2003) report highlighted the problems that poor written communication from DWP can create for claimants. The NAO found that some decision letters may list the reasons for a decision but did not explain the decision in terms of claimants' specific situations. During its inquiry, the Work and Pensions Committee received evidence to suggest that notification letters continued to cause problems. The Work and Pensions Committee also expressed concerns about the quality of decisions letters. The DWP agreed that decision notices need to be improved to support clarity and cost effectiveness and has established a 'Transforming Letters' initiative.

Persons who are dissatisfied with a decision may apply for reconsideration by DWP. 44% of DLA reconsiderations were found in favour of the claimants in 2007-08; this figure rose to 51% in 2008-09. In addition, 43% of DLA cases subsequently reaching an appeal hearing found in favour of the claimant. The Work and Pensions Committee suggested that this indicated 'that reconsideration is still failing to pick

up a large proportion of claims that should be awarded.’ The Committee went on to note that while welfare rights advisers in evidence to the Committee had suggested that the reconsideration process was working well with respect to DLA as a relatively high proportion of decisions are overturned at this stage, ‘these statistics equally raise questions about the quality of the original decisions made in DLA cases. If standards of decision making on initial claims were high then it is logical to expect a low rate of overturned decisions at the reconsideration stage.’

A number of organisations also suggested that claimants often failed to understand how the decision process worked and this was exacerbated by the fact that claimants were rarely given the opportunity to speak to the Decision Maker responsible for the outcome of their claim. The DWP Standards Committee (2007-8) highlighted the findings of the President of Appeals Report 2007-08, which reported that, of all the DLA/AA cases that are presented to appeals tribunals, 40% are overturned. In 73% of the overturned cases the tribunal accepted new evidence at the hearing from the claimant, sometimes in the form of medical evidence and other times it was the claimant's verbal account of living with a disability. In order to try and reduce the number of cases going to appeal, the Standards Committee concluded that a better understanding of the claimant's viewpoint could significantly impact upon the number of appeals that are processed and the number of appeals that are overturned in the claimant's favour. The DWP Standards Committee recommended that:

In all cases that get to reconsideration/appeal the appeal writer/decision maker should ensure they [...] have made meaningful contact with the customer and/or carer before the issue is referred to appeal to ascertain how the customer experiences their disability.

The DWP has decided to run a small pilot to identify the costs and benefits of giving customers a direct telephone number on which to contact staff dealing with their request or appeal. The trial will investigate the costs and benefits of such an approach.

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Annex 1 – Descriptive matrix on payments in six countries studied

Issue	Belgium	Canada	Finland
Name of payment	Allocations familiales majorées pour l'enfant malade ou atteint d'un handicap	Child Disability Benefit	Alle 16- vuotiaan vammaistuki (Disability Allowance for persons under 16 years of age)
What is the objective of this payment?	To assist with the costs of the child's disability	Intended to assist low- and modest-income families with the costs arising from the child's disability	To compensate for the additional strain caused by sickness or disability
How much is the payment?	€77.62-€517.44 per month depending on degree of disability and its impact	Up to \$2,575 per year (\$214.58 per month).	Basic rate (€89,18 per month); Middle rate (€208,09 per month); Highest rate (€403,50 per month)
How often is it paid: per week, per month etc?	Monthly	Monthly	Monthly
At what age does the payment start and stop?	0-21	0-17	0 - 15
Does the payment change as the child ages? If so, how?	No	No	No

	Belgium	Canada	Finland
Does the child progress from this payment to an individual payment?	May qualify for integration allowance	May qualify for Disability Tax Credit and/or provincial/territorial social assistance payments	May become entitled to a Disability Allowance for persons aged 16 years or over or Rehabilitation Allowance
Does the payment change if the child attends school? If so, how?	No	No	No
Does the payment change if the child lives away from home? If so, how?	No	Payable to primary caregivers. Alternative payment where child is cared for in an institution	No
If the family has more than one child with a disability is the payment altered? If so how?	No	No	No
Is the payment available to parents who are working?	Yes	Yes (but subject to income test).	Yes

	Belgium	Canada	Finland
Are the criteria used relating to the child's disability based on			
<i>Medical diagnosis</i>	Yes	Yes	Not solely but medical diagnosis gives KELA information
<i>Degree of care required</i>	Yes	No	Yes, this is the basis of the assessment
<i>Additional costs associated with the disability</i>	No	No	Costs can have an effect, but only when considering the middle rate payment
<i>Threshold of functioning relative to peers</i>	Yes	Yes	No
<i>Other criteria (specify)</i>	See text	None	Residence

	Belgium	Canada	Finland
Does the payment vary with the nature of or severity of the disability or care needs?	Yes	No	Yes
Is this payment assessed using a tiered approach or sliding scale depending on the child's disability and/or care needs?	Tiered	Na	The payment comprises three tiers: The amount of the allowance is tied to the degree of strain and commitment required of the family
How does it interact with other payments or entitlements?	Supplement to child benefit system, insurance based	Part of overall child benefit, non-refundable tax credit	Stand-alone
Which government department/agency is responsible for this payment?	Social security authorities (ONAF)	Canada Revenue Agency	KELA - The Social Insurance Institution of Finland
How many children receive the payment (both in absolute terms and as a % of total children in the age range)	40,000 (1.6%)	Not available	35,000 (3.7%)

	Belgium	Canada	Finland
How much does this payment cost on an annual basis?	€329 (0.046% of GDP)	CN\$220.4 (0.0167% of GDP)	€71.9M (0.038% of GDP)
What are the legal provisions underpinning this payment?	Code de l'action sociale et des familles : annexe 2-4; Code de la sécurité sociale : articles L541-1 à L541-4; articles R541-1 à R541-10	Income Tax Act (Canada)	Disability Benefits Act (laki vammaisetuuksista) - came into force 1-1-2008
What are the other eligibility criteria for this type of payment?	Residence	Income	Residence
Who decides if the eligibility criteria are met, e.g. medical assessment?	Doctor employed by social security agency	Revenue authorities based on review of GP's certification	KELA - The Social Insurance Institution of Finland
Is there detailed documentation available re any medical or other criteria?	Yes	No	Yes

	Belgium	Canada	Finland
How often is the payment reviewed (or reapplication necessary)?	Set by examining doctor but no set period	Not specified	Depends mainly on the child's individual situation
What application process do families have to go through? Include copies of application and assessment forms if applicable	Form is submitted to social security who arrange an examination	Form is completed by claimant and GP and sent to Revenue	Form submitted to social security institution with medical certificate
Is this payment means tested?	No	Income tested on an annual basis	No
Is this payment a standalone payment like the Domiciliary Care Allowance or is it incorporated with other payments such as Child Benefit?	Supplement to child benefit system	Part of child benefit system	Stand-alone

	Belgium	Canada	Finland
If families get this payment do they also get other benefits such as Carer's Allowance or Respite Care Allowance?	No but other benefits available	No	May get other benefits at the same time (see text)
Does the country have an equivalent to the Carer's Allowance payment?	No direct equivalent	No direct equivalent	Yes, special care allowance (see text)
If a family is declared as being ineligible for these payments what other benefits can they apply for? Including but not limited to health, education, care and social services benefits.	See text	See text	See text
Is there an appeals process?	Internal review/appeal to labour court (tribunal du travail)	Internal review/appeal to tax court	Internal review/appeal to court
How often are appeals overturned?	Nk	Nk	25%

	Belgium	Canada	Finland
How much information are claimants given for refusal of appeals?	Written decision	Written decision	Written decision
Has the Government ever reviewed the payments? If so what was the driving factors behind the reviews?	Reformed in 2003 (see text)	Introduced in 2003	2008 reform changed name and terminology but left criteria and amounts largely untouched
Is this payment effective in meeting the support needs of the families and their children with disabilities?	Nk	Nk	Nk

Issue	France	The Netherlands	United Kingdom
Name of payment	Allocation d'éducation de l'enfant handicapé, AEEH	The TOG care allowance	Disability Living Allowance (DLA)
What is the objective of this payment?	Intended to offset the costs of education and caring for a disabled child.	Contribution towards expenses of raising and caring for children who are disabled or severely ill and who live at home	Main benefit for disabled people to help meet any extra costs of being disabled
How much is the payment?	€127,68-€1,210.11 per month depending on related costs and degree of care required	€ 215.80 per quarter	£20.55 (low) - £51.85 (middle) - £77.45 (high) per week (care) and £20.55 (low) - £54.05 (high) per week (mobility)
How often is it paid: per week, per month etc?	Monthly	Quarterly	Every 4 weeks in arrears
At what age does the payment start and stop?	0-19	3 or over and under 18	3 months- 16 years (care) and 3 years - 16 years (mobility)

	France	The Netherlands	United Kingdom
Does the payment change as the child ages? If so, how?	No	No	May become entitled to mobility component at age 3
Does the child progress from this payment to an individual payment?	May qualify for l'allocation aux adultes handicapés	May apply for benefit under the Disablement Assistance Act for Handicapped Young Persons (Wajong)	May progress onto 'adult' DLA if eligibility criteria continue to be met. In future may claim new Personal Independence Payment (PIP)
Does the payment change if the child attends school? If so, how?	No	No	No
Does the payment change if the child lives away from home? If so, how?	Benefits are suspended in case of hospitalisation exceeding one month or where child is in care funded by the State	Must spend 4 nights a week at home, or be in hospital or nursing home for less than 6 months, or away on a holiday. If a child cannot live at home because of the disability, the TOG is not payable but the parent will usually be eligible for Child Benefit at twice the basic rate	When a child is in hospital payment of DLA stops after 12 weeks. In a residential school or care the care component stops after 28 days. The mobility component is not affected.

	France	The Netherlands	United Kingdom
If the family has more than one child with a disability is the payment altered? If so how?	No	No	No
Is the payment available to parents who are working?	Yes	Yes	Yes
Are the criteria used relating to the child's disability based on			
<i>Medical diagnosis</i>	Yes	Yes	Contextual and supporting information
<i>Degree of care required</i>	Yes	Yes	Degree of support needed with personal care for care component
<i>Additional costs associated with the disability</i>	Yes	No	No

	France	The Netherlands	United Kingdom
<i>Threshold of functioning relative to peers</i>	Yes	Yes	Yes
<i>Other criteria (specify)</i>	See text	Primary carer and child must live in Netherlands and former not work outside country	Residence and presence conditions
Does the payment vary with the nature of or severity of the disability or care needs?	Yes	No	Yes
Is this payment assessed using a tiered approach or sliding scale depending on the child's disability and/or care needs?	Tiered	No	Care component x 3 rates depending on amount of care needed. Mobility x 2 rates depending on ability to walk
How does it interact with other payments or entitlements?	Stand alone (see text)	A person in receipt of a TOG care allowance for 12 months or more may also be able to get 'Extra financial support for single-income households'	Not taxable or treated as income for other benefits. Can trigger increase in other benefits and entitlements re transport and employment rights

	France	The Netherlands	United Kingdom
Which government department/agency is responsible for this payment?	Social security (CNAF)	Sociale Verzekerings Bank (SVB) The Social Insurance Bank	Department for Work and Pensions
How many children receive the payment (both in absolute terms and as a % of total children in the age range)	191,800 (1.2%)	30,000 (1%)	335,000 (2.9%)
How much does this payment cost on an annual basis?	€680M (0.040% of GDP)	€22.4M (0.0037% of GDP)	£1240M (0.086% of GDP)
What are the legal provisions underpinning this payment?	Code de la sécurité sociale : articles L541-1 à L541-4	National Act on Exceptional Medical Expenses (AWBZ).	Social Security Contributions and Benefits Act 1992; Disability Living Allowance and Disability Working Allowance Act 1991 and The Social Security (Disability Living Allowance) Regulations 1991
What are the other eligibility criteria for this type of payment?	Residence	Parent must live or work in the Netherlands and not receive equivalent compensation	Residence and presence conditions

	France	The Netherlands	United Kingdom
Who decides if the eligibility criteria are met, e.g. medical assessment?	Commission des droits et de l'autonomie des personnes handicapées (multi-disciplinary team)	Sociale Verzekerings Bank (SVB) The Social Insurance Bank	DWP Decision Maker (see text)
Is there detailed documentation available re any medical or other criteria?	Yes	Yes	Yes
How often is the payment reviewed (or reapplication necessary)?	Can be awarded for periods of between 1-5 years depending on nature of disability, etc.	Between 3 months and 5 years depending on nature of disability, living circumstances and whether approaching a relevant age threshold for eligibility.	Awards can be made for any duration and can be indefinite or for a fixed period. The vast majority of child claimants have a fixed award (96%).
What application process do families have to go through? Include copies of application and assessment forms if applicable	Claim form and medical certificate submitted to CDAPH who consider application	Application with the AWBZ indication for the child to the Social Insurance Bank (SVB) (see text)	Form or on-line (see text)

Is this payment means tested?	No	No	No
	France	The Netherlands	United Kingdom
Is this payment a standalone payment like the Domiciliary Care Allowance or is it incorporated with other payments such as Child Benefit?	Stand alone	Stand-alone	Stand-alone
If families get this payment do they also get other benefits such as Carer's Allowance or Respite Care Allowance?	No but other benefits available	Not a passport benefit	If child gets middle or highest rate of the DLA care component, may be able to get carer's allowance
Does the country have an equivalent to the Carer's Allowance payment?	No direct equivalent but higher rates of AEEH provide compensation where parent has to leave work	No direct equivalent	Yes, carer's allowance (see text)

If a family is declared as being ineligible for these payments what other benefits can they apply for? Including but not limited to health, education, care and social services benefits.	See text	If a child cannot live at home because of the disability, the TOG is not payable but the parent will usually be eligible for Child Benefit at twice the basic rate	See text
	France	The Netherlands	United Kingdom
Is there an appeals process?	Appeal to specialist incapacity tribunal (tribunal du contentieux de l'incapacité)	Internal review/appeal to court	Internal review/appeal to tribunal/court
How often are appeals overturned?	Very few appeals to court	Very few appeals to court	c.40% (see text)
How much information are claimants given for refusal of appeals?	Written decision	Written decision	Written decision
Has the Government ever reviewed the payments? If so what was the driving factors behind the reviews?	No recent review	Since 2010 child must have CIZ decision showing need for care for 10 hours or more per week (see text).	Currently being reformed for working age claimants (see text)

Is this payment effective in meeting the support needs of the families and their children with disabilities?	Nk	Nk	See text
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