COMPENSATING EXTRA COSTS FOR PERSONS WITH DISABILITIES THROUGH ECONOMIC EQUALITY: THE U.S. AND SWEDISH LEGAL APPROACH IN A HUMAN RIGHTS PERSPECTIVE

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COMPENSATING EXTRA COSTS FOR PERSONS WITH DISABILITIES THROUGH ECONOMIC EQUALITY: THE U.S. AND SWEDISH LEGAL APPROACH IN A HUMAN RIGHTS PERSPECTIVE

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When we do the best that we can, we never know what miracle is wrought in our life, or in the life of another. Until the great mass of the people shall be filled with the sense of responsibility for each other’s welfare, social justice can never be attained.

Helen Adams Keller

Introduction

The United Nations has determined that 10 percent of the world’s population is disabled. Of this 10 percent, 80 percent of persons with disabilities live in developing nations. In the U.S., 12 million Americans with disabilities receive either Social Security Disability Insurance or Supplemental Social Security benefits. Considering the UN statistic, an estimated 31 million Americans have disabilities, leaving 19 million completely uncovered by benefits. In Sweden, in 2012, 486,085 Swedes with disabilities received benefits. Considering the UN statistic and Sweden’s population of 9 million, 413,915 Swedes with disabilities did not receive any benefits. In addition to the daily challenges a person with a disability must face, and the barriers and difficulties in seeking and obtaining benefits, persons with disabilities can incur costs that are directly related to their disabilities, and which are often not publicly sponsored through health care insurance, such as Medicare and Medicaid in the U.S. or through targeted support and services administered through the Swedish central government, county councils and municipalities. For purposes of this article such un-covered and un-reimbursed expenses are referred to as “extra costs.”

In this article we present some of these challenges, discuss policy and government administration issues, and provide suggestions to improve current policy regarding disability benefits.

¹ Richard Sahlin is an externally financed researcher and teaching occasionally public law at law faculty, Stockholm University. I would like to thank Professor Michael Perlin who invited me to give a lecture on my research result at New York Law School during the Spring 2013. The professor has also read this article that is mainly based on my monograph. See Richard Sahlin, Merkostnader för försäkrade genom värdbidrag eller handikappersättning: Frågan om Försäkringskassans uppdag och ansvar (Extra costs for insured through child care benefit or disability benefit: A Question of the Swedish Social Insurance Agency’s Mandate and Responsibility)(2012).

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Overview

There are two main factors that create a causal relationship between disability and poverty. The first factor is the extra costs that persons with disabilities must pay out-of-pocket. The second factor is the typified lower income of persons with disabilities compared to able workers. Rates of low-income employment, unemployment, and sick leave are higher among persons with disabilities than abled persons in the workforce. This study considers the causal relationships and effects upon people with disabilities who have great financial difficulties paying for “extra costs.” This economic problem has been addressed by World Bank studies in many areas. Although these studies mainly focus on developing countries, the Organization for Economic Co-operation and Development (OECD) and domestic statistical studies generally show that the majority of poor people have a cognizable disability.

These studies clearly conflict with postmodern disability policy on economic equality. According to this policy, disability should not have any adverse impact on a person’s budget and financial health. Irrespective of any disability an individual should have equal economic opportunities. This form of equality originated in Aristotle’s principle of equal treatment. Equal entities should be treated equally (formal equality) and unequal entities should be treated unequally with regard to any inequalities (substantive equality). Disability is a distinguishing characteristic that can be the basis of disparate and, all too often, discriminatory treatment. This principle is ethically rooted in a fundamental rule of law and human rights. It should be noted that not only direct medical costs, but other factors, such as personal care, transportation and family care may impact the amount of extra costs. For example, women with disabilities generally have higher extra costs, such as cosmetics, jewelry and hairstyling, than men with similar disabilities. Similarly, high earners with disabilities often have higher extra costs, such as property maintenance for their housing, luxury items and overseas traveling, than low earners with disabilities. Certainly, a system in which persons with disabilities are able to buy luxury

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7 See, e.g., Avgifter inom handikappområdet (Fees within Disability Area), Statens Offentliga Utredningar SOU 1995:35. (Government Report Series, Swed.).
items on an equal basis with rich persons without disabilities may arouse a moral suspicion. However, the main focus of this article is not relative personal wealth, but rather the disparate treatment of persons with disabilities. Why should persons with disabilities not be entitled to compete in the economic market equally to persons without disabilities? Therefore, the goal of this research is to provide the analysis and justification to level the economic playing field for all persons irrespective of any varying degrees of disability or economic means to pay for “extra costs.”

To resolve or at least lessen the economic chasm between people with disabilities and people without disabilities, a general survey shows that many countries have introduced a set of legal measures such as discrimination prohibition, affirmative action, universal design, and social security/insurance programs. Of these measures, the government compensation scheme will be considered in this article. - Our goal is not to pursue a comparative study of all domestic compensation schemes but to focus on two domestic schemes and how they relate to treaties on human rights and postmodern disability policy. The U.S. and Swedish compensation schemes will be chosen due to their ideological polarity, i.e., classical liberalism versus socialism/social solidarity. To understand to what extent persons with disabilities are compensated for their “extra costs,” this article will delve into the following essential areas:

First, some central features of the compensation scheme will be identified and discussed on a theoretical plane. These features will be used as a point of departure to describe and analyze the content of treaties on human rights and domestic legislation. Next, the relationship between these normative documents will be examined and discussed. In this context it should be noted that the U.S. has two parallel legal systems, i.e. federal and state governments, in contrast to Sweden, which has a unitary system. It is the federal legal systems of both countries that will be the focus of this article.

A Theoretical Framework of Compensation Scheme

There are several theoretical aspects that legislators should consider to establish and design a compensation scheme for persons with disabilities. For purposes of this article, we shall not discuss all aspects but focus on the following five areas: terminology, methodology, legitimacy, division of duty and priority-based budgeting. These factors may play a central role to determine the viability and scope of the scheme. To illustrate abstract concepts, principles and rules, we focus on extra costs that persons with hearing and visual impairments are likely to incur. Persons with disabilities are a heterogeneous group with varying needs and preconditions and it is not possible to consider them all.

Terminology

A compensation scheme should include at least three central concepts: disability, extra costs and compensation. The first two concepts, disability and extra costs, are legal factum (factual circumstance, premise or criterion), which are found in the first part of a rule of law. The last concept, compensation, is a legal consequence (effect or result), which is found in the second part of a rule. A rule of qualification is drafted in the following way: If a person satisfies two legal criteria (disability

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9 A treaty is an agreement that can only be concluded by sovereign states and/or inter-governmental organizations.
and extra cost) then he or she is entitled to a certain form of compensation. One problem is that these concepts can have different meanings depending on their contextual origins such as common parlance and scientific theories. To avoid this confusion, it is necessary for law makers to define each concept. Otherwise, there is a risk that the interpretation and application of the intent of the legislation may be misaligned with the original intent of the legislation. Accordingly, we will discuss the appropriate definitions of these concepts and the legal consequences for the scope of a compensation scheme.

2.1.1 The Concept of Disability

Suppose policymakers wish to establish a compensation scheme, which is only available to persons with disabilities.\(^{10}\) To distinguish these intended beneficiaries of the law from others, it is necessary to define the specific parameters of “disability” as it is to be used in the law. History shows that there are at least three theoretical models that give disability a certain meaning.\(^{11}\) Traditionally, the medical model of disability has been the dominant defining concept. According to the medical model, disability is a problem that is directly linked to a person’s medical state. A person with a hearing impairment cannot hear because of his or her hearing loss, and a person with a visual impairment cannot see because of his or her visibility loss. To cure or at least reduce the effect of their disability, it is a matter of professional discretion to prescribe individual measures such as medication, surgery and rehabilitation. For instance, a person with a hearing impairment may undergo surgery to improve their hearing with cochlear implants. Likewise, a person with a visual impairment may use a guide dog. During the late 1960s and 1970s, disability activists criticized this model for overlooking the risk of professionals oppressing persons with disabilities’ dignity and autonomy. More exactly, professionals generally determine a person with a disability’s fate by assuming what is best for them in respect to education, employment and housing. To address this problem, disability activists have established a social model of disability. According to this model, disability is a problem that can be caused by societal structure. Persons with disabilities may experience physical or social barriers. An example of a physical barrier is that a person with a hearing impairment may not enjoy a movie in a theater because films are not subtitled. A social barrier is that a person with a visual impairment is unemployed because of negative attitudes from the employer about his or her work capability. By introducing discrimination prohibition and accessibility standards these barriers can be removed so that persons with disabilities can participate in society comparably to persons without disabilities.

These two models conflict in that, under the first model, a person with a disability adapts to preconditions of society, while under the second model, society adapts to a person with disability’s needs. In reality, these two models should be merged into one holistic model to provide the greatest accessibility for persons with disabilities. No matter how accommodating a society is to persons with disabilities, there are always certain people with disabilities who have particular needs, such as hearing aids for persons with hearing impairments and guide dogs for persons with visual impairments, which may not be covered or reimbursed by insurance. It is not until the early 2000s that the World Health Organization (WHO) merged these models to a holistic and relative model – the biopsychosocial model of disability – through a new international classification of Functioning,

\(^{10}\) See generally Sahlin, supra note 1, at 19 -24 (for a more in depth analysis).

\(^{11}\) See, e.g., Tom Shakespeare, What is a Disabled Person, Disability, Divers-ability and Legal Change, at 25-34 (Melinda Jones & Lee Ann Basser Marks eds., 1999).
Disability and Health (ICF). According to this classification, disability is a singular term often used to describe limitations such as impairment, activity limitation and participation restriction. This can be contrasted with functioning, a term used to describe elements such as body functions and body structures, activity and participation, which could mitigate a disability. These concepts are dynamic and interrelated through contextual factors that are non-health-related (personal and environmental factors). Therefore the classification recognizes that it is not possible to draw a boundary between disability and functioning, but that each person is unique based on medical status, interest, talent and surrounding environment.

Out of these models, the medical model is considered the most appropriate legal definition to determine who is covered by a compensation scheme, thus, allowing only those who are truly disabled to receive certain forms of compensation, also known as the personal scope. The medical model is the most objective of all the models in the sense that it provides a clear boundary between disability and functioning. The problem is that there is a spectrum of human abilities from no disability to total disability. By using four main medical criteria it is possible to assess the medical effect on an objective ground, i.e. cause, type, severity and duration. Without such criteria, there is always a risk that people can take advantage of the compensation scheme, which would cause a disproportionate burden on a duty-bearer (e.g. the state). However, the biopsychosocial model should be used as a test to determine that the medical effect is not over or under inclusive. For example, two persons with hearing impairments may have variant extra costs despite the fact that they have the same type, degree and duration of hearing loss. Non-health factors can explain how one person with a hearing impairment can have a unique talent to use voice and read lips, while another person with a hearing impairment lacks such a talent. The latter person will incur an interpreting cost to be able to communicate with a person who does not know sign language, while the first person may rely on lip reading. This example shows that the biopsychosocial model will ensure that a legal application of the concept of disability will not collide with the proportionality principle, which is fundamental to the rule of law. According to this principle, a means must be reasonably proportionate to its objective. In other words, the personal scope of a compensation scheme should be used as a reasonable means to attain economic equality. More exactly, only those who actually or potentially incur extra costs should be compensated.

2.1.2 The Concept of Extra Cost

It is also necessary for legislators to clarify the concept of extra cost with the intention of determining what the compensation scheme covers for persons with disabilities. As mentioned in the introductory section, we have defined the concept as a cost which is caused by a person’s disability and which is not already publicly sponsored through targeted support and/or service. This definition consists of two parts. First, there must be a causal link between a disability and a claimed

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13 Despite the fact that the biopsychosocial model of disability is universally recognized, it does not translate into domestic statutes. The problem is that legislators must adapt the model of disability to the objective of each statute. If the biopsychosocial model were used for social security legislation, there is a risk that anyone could claim a disability. If so, this would place an unfair financial burden on society to compensate all extra costs. Therefore, the medical model can be appropriately used as a legal definition to determine the personal scope of a compensation scheme. Only those who are truly disabled are entitled to a certain form of compensation.


15 See generally Sahlin, supra note 1, at 24 -26 (for a more in depth analysis).
cost, otherwise, it is a cost that everyone incurs irrespective of disability, or a *normal cost*. Second, a cost must not already be covered by other publicly sponsored supports and/or services, which are insufficient to satisfy all the needs of people with disabilities. In this subsection we will focus on the first part because the second part does not focus on terminology, but on legal relationships between persons with disabilities and duty-bearers.\(^{16}\) What constitutes a cost is necessary to understanding this issue. In contrast to disability there is no universally recognized definition of the term cost, but dictionaries provide a list of definitions with different meanings. I find Black’s Law Dictionary’s definition most appropriate. According to this definition, a cost is “the amount paid or charged for something.” This definition exemplifies that the concept has a broad meaning that encompasses all areas of economic life.\(^{17}\) To make the cost system more accessible, some scholars have categorized cost utilizing a comparative analysis:

**General cost v. special cost:** A general cost refers to a cost that all people irrespective of disability incur to be able to live, such as general housing, clothing and food. A special cost refers to a cost that only certain people with disabilities incur, such as housing adaptation, tailored clothing and fat-reducing food.

**Higher cost v. lower cost:** A higher cost refers to an increased cost that people with disabilities pay in comparison to people without disabilities. For example, a person with a hearing impairment must pay higher traveling costs to have a direct communication with a physician that is not available near his or her place of residence. A lower cost is the reverse and seldom occurs. One example is that some persons with disabilities avoid traveling abroad because the flight is inaccessible. This ensures they do not incur any flight-related costs. Another example is that persons with disabilities are granted a concession on entrance fee to museums, thus, incurring lower costs than persons without disabilities.

**Capital cost v. recurring cost:** Capital costs refer to costs that are spread over a number of years. One example is costs for auxiliary aid and housing accommodation with a duration of at least one year. The purpose of capital costs is to offset these measures annually. Recurring costs refer to costs for goods and services that are consumed continuously, such as costs for fat reduced foods and electrical bills.

**Direct cost v. indirect cost:** A direct cost is easily identified because of the direct causal link between a person’s disability and certain costs. Examples of direct costs are, hearing aids for persons with hearing impairments and sticks for persons with visual impairments. If such costs are indirectly linked, they are considered indirect costs. For example, persons with disabilities may be involuntarily unemployed or granted a non-paid leave for a medical examination due to disability. As a consequence, they receive lower income and ability to budget their costs.\(^{18}\)

**Actual cost v. potential cost:** An actual cost, also referred to as a historical cost, is a cost that a person has already incurred. Thus, an actual cost compels a person with a disability to show his or her extra costs through invoices, household bills, entrance fees, and etcetera. A potential cost, also referred to as a future cost, compels a person with a disability to argue why his or her disability

\(^{16}\) See infra Part 2.4.

causes a certain cost that is typical for all persons with similar disabilities, such as providing a detailed description of his or her budget. The purpose is to receive a benefit to cover this potential cost.

Ordinary cost v. opportunity cost: An ordinary cost is a cost that is so typical as to render a person with a disability unaware that he or she has any costs, such as food and clothes washing expenses. An opportunity cost is a cost that a person with a disability incurs without any preparation in certain circumstances. For example, persons with disabilities in Sweden may take advantage of campaign price to go on holiday abroad. Such a cost, which is provisional and impulsive, arises for them.

It should be noted that one single cost could be identified under multiple categories. For example a person with a visual impairment can incur dog-related costs, which are identified as special, higher, recurring, direct, actual and ordinary costs. For policymakers, it is necessary to clarify whether the concept will cover all or a few categorical costs. This will have a central impact on the legal scope of the compensation scheme.

2.1.3 The Concept of Compensation

Like the concept of cost, there is no universally recognized understanding of the concept of compensation. For our purposes, Collins English Dictionary provides a relevant definition. According to the Collins English Dictionary, compensation is “the act or process of making amends for something.” By applying this definition to disability law, all legal measures can be covered, which aims to remove all barriers that people with disabilities face in society, such as prejudices (discrimination prohibition), inaccessibility (affirmative action and universal design), and social insurance and social security (economic assistance). This article focuses upon the concept as it generally refers to a last resort, where a person with a disability will get financial assistance to cover extra costs other targeted public supports and/or services fail to provide. This financial assistance can be designed in different ways:

A benefit is financial aid given to a person with a disability through a social agency such as social insurance and social security. To avoid minor and trivial costs associated with administration, legislators should introduce benefit levels. A person with a disability is required to pass a threshold to reach a certain level; however, such a level can cause problems with over and under inclusiveness. If a person with a disability is required to submit bills and fees to get a benefit, there is a risk that this will disfavor those who cannot afford to compensate such costs. Thus the benefit can be criticized as a benefit given based on class. By contrast if the benefit covers potential costs, it can promote individual autonomy. A person with a disability has a greater opportunity to utilize the benefit to cover such measures he or she prefers than if he or she is only given a certain type of target-determined measure. Certainly there is a risk that this person will choose a measure that is not necessary. For instance, this person could choose to spend this allotment on items that do not directly support or aid their disability.

18 See generally Sahlin, supra note 1, at 29-32 (for a more in depth analysis).
19 See supra Part 1.
20 See supra Part 2.1.1.
21 See supra Part 2.1.2 (about actual costs).
22 Id. (about potential costs).
A tax credit (deduction) is financial aid a person with a disability claims, either through local, state and federal taxes in the U.S., or at any tax agency in Sweden. This credit can consider all or a few extra costs and be proportionate or progressive depending on a person’s income. One benefit of a tax credit is that it provides an economic incentive to persons with disabilities to profit from hard work. However, tax credits may be unfair to those who are involuntarily unemployed or lack any resource.

A concession is financial aid a person with a disability claims through any public or private service provider. This concession can reduce or eliminate household bills, travel expenses and fees for sporting activities. This is seen as a way to spread the duty to the community as a whole, thus improving social solidarity. To use these benefits, a person with a disability may be required to submit verification (often in the form of a card or other identifying documentation) provided by a public agency. Generally, a person must also submit medical documentation to certify his or her disability. One benefit of a concession is that it recognizes that many persons with disabilities need to use certain public services, agencies or other public organizations more than others, such as swimming pools for habilitation or rehabilitation. Another benefit is the recognition that persons with disabilities have financial difficulties as a result of structural discrimination. It is not easy to identify the breadth of structural discrimination; thus, a concession is generally used as a final means of compensation for persons with disabilities. However, concessions can cause problems with under or over inclusiveness. Certain persons with disabilities who have limited opportunities to utilize public service funding may be disfavored. This is particularly problematic for those who live in rural areas where infrastructure is limited.

A scholarship is financial aid that is administered to persons with disabilities by a public or private non-profit organizations on behalf of donors. The state or other actors can donate funds to enable organizations to assess who is qualified to receive a certain amount of money. The main purpose of a scholarship is to simplify the application procedure by giving the organization a flexible assessment. However, there is a risk that the outcome will be unpredictable and unfair for some.

All these forms of compensation have their benefits and detriments. Of course, there is nothing to prevent legislators from combining multiple compensation measures. However, it is important that legislators clarify how each form of compensation relates to the other forms, whether multiple types of compensation can be claimed together, or if certain types of compensation are mutually exclusive.

2.2 Methods of Cost Assessment

It is not enough for legislators to simply identify the concepts of disability and extra cost, per se but it is critically important to also discuss their mutual relationship. Assuming an extra cost can be a direct or indirect cause of a person’s disability, the question arises how this causal link should be determined. Is it enough that a person with a disability be permitted to calculate his or her extra costs? This would utilize a subjective method. This approach assumes a person with a disability knows best about his or her costs, i.e. is an expert on his or her own living. However, the main risk is that the person may exaggerate his or her costs to be able to get the most compensation possible. There is also the risk that a person with a disability is unaware these are “extra costs” because they are ordinary costs. Without such an awareness, the person does not know the means of applying for

23 See supra Part 2.1.1.

24 See generally Sahlin, supra note 1, at 27 -29 (for a more in depth analysis).
assistance or if they are even eligible at all. To avoid this problem, advocates and legislators should require medical documentation to qualify for compensation.

Is it reasonable to assume that medical staff can identify and assess these extra costs better than democratically elected policymakers.25 A physician often receives specialized training in identifying extra costs his or her patient may incur and incorporate them into a plan of care. According to the physician, such extra costs may be necessary to promote the patient’s health and to establish an optimal and confident relationship between patient and physician. Another physician could refuse to issue a medical statement because it may be too hard to assess a patient’s extra costs that are not clinically validated or scientifically proven. The problem is that no researcher is expected be able to determine the exact amount of extra costs because this varies significantly between persons with disabilities.26 To avoid the risk that a person with a disability is unsuccessful in obtaining an appropriate recommendation from a certain physician, legislators should give the person with a disability an option to offer a second-opinion from another impartial physician or other medical professional and have it given the weight and effect of all other medical opinions and diagnoses. For example, when a physician has expanded knowledge of living conditions of persons with disabilities, there is a much greater chance that extra costs relating to a disability will be considered and even paid for as a result. Without an expanded scope of such an analysis, there is a risk that physicians may not understand why non-health factors could lead the person to incur extra costs, resulting in an effective denial of medical and financial assistance necessary for optimal assistance.

To reduce the arbitrary nature of the subjective method, policy makers can use a more objective method method: the comparative method. For this approach, two groups – one with persons with disabilities and one without – are compared with each other. Members in each group have similar income levels and are evaluated to assess how much money they spend on a selection of goods, services and housing to be able to attain an adequate standard of living. The goal is to determine how much household spending differs between people with disabilities and people without disabilities.

One problem with this comparison is that it does not consider cases in which persons with disabilities need items that are not covered by the selected sample. People with disabilities may need auxiliary aids that persons without disabilities do not need. Without such a limitation, there is a risk that people with disabilities would spend money on luxury food rather than to finance costs for auxiliary aids. Another problem is that it is difficult to compare group members of variant family sizes. Certain extra costs can be shared amongst household members in larger families. A third problem is that it is somewhat subjective to determine what standard of living is considered to be adequate.

To remove some of the limitations of the comparative approach, better results can be achieved if advocates or legislators utilize both methods simultaneously. The objective method can be used as a starting point for determining the amount of extra costs appropriate to people with a similar type, severity, and duration of disability. Such a method is possible if legislators authorize an impartial evaluation to provide statistical data on household bills typical for persons with disabilities. This data can reflect costs for certain groups of persons with disabilities, such as fat-reducing food and heating costs for persons with diabetes or muscular disorders, respectively. This combined method can rationalize administrative procedure by allowing a public entity to apply a standard assessment of a certain type of disability to determine the size of extra costs; otherwise, it would be very time and

26 See supra Part 2.1.1.
cost consuming to determine each causal link between a claimed cost and a disability that a person has, i.e. individual assessment. To avoid problems with under and over-inclusiveness that a standard assessment can cause, it is necessary to allow a person with a disability to provide documentation to prove that he or she has additional costs than what a standard assessment shows.\(^{27}\) Therefore, both methods are necessary to prevent either unfairly advantageous or disadvantageous compensation.

### 2.3 The Legitimacy of Compensation

No compensation scheme can survive without social consent in a democratic society.\(^{28}\) Adult citizens are entitled to vote for policymakers they believe are best to govern a society (legislators). If some are unsatisfied with a certain compensation scheme, they can exert some political influence, such as dialogue, lobbying efforts and endorsements on policymakers to amend or abolish it. In any enlightened society, it is important that advocates and legislators design a compensation scheme that will not give an unfair disadvantage to persons with disabilities.\(^{29}\) TO make this most effective, it is necessary to discuss whether there are grounds to justify a compensation scheme that is only available for persons with disabilities. Will this scheme be accepted by persons who are not covered by it?

As a point of departure for this discussion, it is necessary to examine the social contract theory that famous philosophers such as Thomas Hobbes (1588-1679) and John Locke (1632 -1704) established.\(^{30}\) According to this theory, individuals are considered to be social beings who realize that human cooperation (“the state”) is necessary for their wellbeing. They are ready to sacrifice some degree of freedom by performing certain duties such as attending compulsory education, being self-sufficient through their own work, and participating in the military service. In return the State consents to provide them protection. The purpose of a social contract is to rationalize collective human labor over individual self-sufficiency. How far the state should protect the citizenry can be controversial. It is not our objective to discuss all legal ideologies, but rather to focus on two divergent goals and to relate them to the raison d’être of a compensation scheme.

The first ideology is classical liberalism, established by Adam Smith (1723- 1790) and Jeremy Bentham (1748 -1832), which is based on the idea that the state should only be a watch to ensure that no person is attacked by establishing fundamental agencies such as defense, law enforcement and judicial agencies. The state should respect the market economy to support the hard work and productivity of its citizenry, as far as possible. This will also favor persons with disabilities because hard work will promote social development by allowing the formation of better medical and technical support for persons with disabilities. Such a compensation scheme does not have its raison d’être because it requires that the state finance it with tax revenue from those with and without disabilities. Increasing the tax rate can certainly have a negative impact on productivity and work ethic, thus forcing persons with disabilities to rely on charity from relatives and hard workers who feel a moral responsibility to compensate their extra costs. Should a person acquire a disability later in his or her life, it is his or her duty to take out insurance that protects him or her against such a disability. The goal is to respect individual freedom as much as possible.

\(^{27}\) See supra Part 2.1.1 (under-and-over inclusiveness).

\(^{28}\) See generally Sahlin, supra note 1, at 32 -37 (for a more in depth analysis).

\(^{29}\) See supra Part 2.1.1.

\(^{30}\) See Thomas Hobbes, Leviathan (1651); John Locke Two, Treatises of Government (1690).
The second ideology is socialism (social solidarity), which is based on the idea that the state has a particular duty to reduce social injustice. John Rawls (1921-2002) argued that through socialism’s famous “veil of ignorance”, most people who do not know about their own preconditions prefer that the state redistribute available resources favorably to those who are most vulnerable. This is based on a presumption that people have a risk aversion and are afraid of acquiring an disability that may lower their standard of living. Therefore, under this ideology, a compensation scheme has its raison d’être. Postmodern philosophers, in particular functionalists such as Amartya Sen (1933 -) and Martha Nussbaum (1947 -), have criticized these conflicting ideologies. According to Sen and Nussbaum, classical liberalism and socialism are too materially fixed to assess what is best for the state. Instead, they believe the state should redistribute available resources to promote persons to utilize their capabilities to function in a society. The state should compensate extra costs for persons with disabilities provided that these costs enable them to participate actively in society. For instance, in the case that a person with a hearing impairment incurs an extra cost to finance his or her interpretation costs, the state could provide compensation, enabling him or her to give a speech to those who do not know sign language. This is seen as a means of enabling persons with disabilities to be independent and self-sufficient in society.

2.4 Division of Duty

According to Wesley Newcomb Hohfeld, the right to a form of compensation should correlate to a duty. If we focus on a duty-bearer, the question arises as to whether it is appropriate to impose a legal duty on a private entity to compensate extra costs for persons with disabilities. However, care must be taken with regards to human rights protections if there is no underlying legal relationship between a person with a disability and a certain private entity. Protection of property is recognized as a human right in democratic and capitalist societies. Instead, it is more appropriate to impose a legal duty on the state. As previously mentioned, a compensation scheme should be used as a last resort should publicly-sponsored, targeted support and service fail to satisfy specific needs for persons with disabilities. To find out which public entity is obligated to provide a certain measure, it is necessary to identify which entity is a duty-bearer; otherwise, there is a risk that a person with a disability will either be over or under compensated. Such a question is not relevant in a primitive society where there is only one public entity that is obliged to perform all measures (the state). In such a society, the state can control which measures it has or has not already taken. Conversely, in many countries, the government generally establishes a complex structure of public entities with different levels and tasks. The objective is to rationalize public support and service. Such a structure can be vertical, meaning there is a set of public entities that represent a certain geographical area from national to regional to local areas. The level most appropriate to deal with a certain measure is

31 The “veil of ignorance,” is a concept that has been in use by other names for centuries by philosophers such as John Stuart Mill, John Rawls, and Immanuel Kant whose work discussed the concept of the social contract. John Harsanyi helped to formalize the concept in economics. The modern usage was developed by John Rawls in “A Theory of Justice.”

32 Wesley Newcomb Hohfeld, Some Fundamental Legal Conceptions as Applied in Judicial Reasoning, 16 Yale L.J. 23, 28 (1913); see also Sahlén, supra note 1, at 41 -44.


34 See supra Part 2.3.

35 See supra Part 2.1.3.
dependent upon what the state values most. A national entity may be most appropriate because it has the ability to ensure all persons, regardless of where they live in the nation, will be treated equally. By contrast, a local entity may be most appropriate because it has greater knowledge of local conditions and needs. For instance, a rural area can be less accessible to persons with disabilities, thus increasing extra costs in comparison to an urban area. One possible explanation for this is that it is very costly to adjust a physical environment due to low population. However, it is often less bureaucratic for a person with a disability to have direct contact with a regional or local entity than indirect contact with a national entity through intermediate entities.

Another way to structure the state is horizontally, meaning a set of public entities represents certain subject matters such as education, employment, social security, health and medical care. The goal of a horizontal structure is to be more effective by specifying certain measures. According to postmodern disability policy on responsibility and financing, all public and private entities should finance disability-specific measures as part of their general costs to finance their respective services. This is seen as a universally consensual responsibility where disability-related costs are not separated from general costs. However, some measures can overlap multiple duty areas. For example, a computerized aid can assist a person with a disability with study, work or errands. There is a risk that an education provider, employer and health and medical provider disagree on which of them should finance a certain measure. One solution is to impose a legal duty on all of these entities to finance the measure on a mutual basis. Another solution is for the state to finance this measure by the compensation scheme as a last resort. However there is a risk that it will be an economic incentive for the disputing entities to fail to reach consensus in order to pass the duty onto the state. This risk can be eliminated if policymakers entreat the state to make recourse before the court to dissuade providers from evading their primary duty.

As a consequence, it is necessary first to determine the legal scope of each public entity’s primary duty before determining the legal scope of the state’s secondary duty to compensate extra costs for persons with disabilities. All criteria of each support and service measure should be studied with accuracy. Such criteria can be divided into two main types: material and formal. Material criteria explain who is entitled to a certain measure, which public entity is under a duty to provide it and what this measure covers. Formal criteria describe enforcement such as litigation, sanction and supervision. A person with a disability may need to go to a court to force a duty-bearer to satisfy his or her disability-related needs. To prevent a provider from evading its primary duty, the court should be empowered to impose a sanction on the duty-bearer. Sometimes, persons with disabilities may be unaware of their rights. To avoid missing the compensation scheme, an independent public entity should be entitled to investigate whether or not a duty-bearer fulfills its primary duty. This can be evidenced by the fact that the state as a final duty-bearer requires a person with a disability to apply for certain disability-related measures for which another duty-bearer has a primary duty. Although a legal document imposes a duty on this duty-bearer, there is no enforcement mechanism to prevent the duty-bearer from evading their duty. As a result, a person with a disability will not be compensated, as their right to compensation is legally contracted, yet in reality is unenforceable.

2.5 Priority-Based Budgeting

36 See, e.g., Kultur för alla (Culture for Everybody), Statens Offentliga Utredningar SOU 1976:20 (Government Report Series, Swed.).
Any compensation scheme requires some financial sacrifice from the state or other public entity.\(^{37}\) To find out whether the state has enough resources to finance a scheme, it is necessary to establish a budget plan consisting of two parts. The first part is public income, which includes tax revenue, interest on loans and property returns. The second part is public spending, which includes all expenses to establish infrastructure such as defense, transportation, education, health and medical care, and social security. The optimal goal is for income and spending to be balanced. If income is less than spending, a budget deficit arises, and it would be unfair to impose a legal duty on future generations to solve this deficit problem. Legislators that choose to increase income to cover spending must be aware that a financial crisis can arise. It is through work that tax revenue is produced. Increasing tax rates can dissuade persons from working overtime to cover these costs.\(^{38}\) As a result, there is a risk that income will decrease despite the increase in tax rates. It is more appropriate for legislators to determine how resources should be redistributed, and to what extent these resources should finance general measures that are necessary to establish a social infrastructure. There is, however, still a risk that these resources will not be sufficient to finance individual measures that vulnerable groups such as persons with disabilities, children, elderly, homeless persons, addicts and immigrants need. Suppose that legislators decide to assign resources to a certain vulnerable group. The question now is which vulnerable group should be given a priority. The ethical platform for priority provides some guidance on this matter.\(^{39}\) This platform includes three principles to determine how human needs should be assessed and ranked. The first principle of human dignity determines that all persons are equal irrespective of their origins and abilities, thus, all persons irrespective of disability are of equal worth. The second principle of need and solidarity determines that priority should be given to those who are considered to have greater needs than others. For example, a patient with a deadly diseases should be given priority to receive medical care in relation to a person with a hearing impairment who only needs a certain form of compensation to finance his or her costs for speech therapy or hearing aids. The third and last principle of cost effectiveness determines that priority should be given to a measure that is equal to other measures that are more costly (rationality). Although a person’s preference should be respected as far as possible in a democratic society, the benefits of a certain measure must be weighed against its cost. This means that the state should weigh the proportionality of a person’s needs against available resources to find out which measure should be given priority.\(^{40}\) This platform reflects that most people feel a moral responsibility for the state to give priority to those most vulnerable groups irrespective of disability as long as it is cost-effective.\(^{41}\)

3 Compensation and Human Rights

Compensating extra costs for persons with disabilities is identified as a social right within the framework of human rights. This means that a person with a disability has a fundamental right to be compensated by the state.\(^{42}\) The state has a legal duty to correct social injustice through this

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37 See generally Sahlin, supra note 1, at 37-41 (for a more in depth analysis); See supra Part 2.4.

38 See supra Part 2.3 (about classic liberalism).


40 See supra Part 2.1.1.


42 See supra Part 2.3 (about social contract theory).
measure. The question is to what extent persons with disabilities can rely on treaties on human rights to claim that the U.S. and Sweden are obliged to compensate their extra costs. The most relevant treaty on this issue is the Disability-Specific Treaty that the United Nations (UN) adopted in 2006 after intense lobby efforts from disability activists during the 1990s. Both the U.S. and Sweden have signed, but only Sweden has ratified it. The U.S. ratification process has stalled because of congressional debate on the relationship between the treaty and U.S. sovereignty, and how the treaty should be interpreted. According to treaty law, the U.S. is legally bound to refrain from acts that would jeopardize the objective of the treaty. However, the problem is that the UN is a relatively powerless global inter-governmental organization. This organization must consider all legal cultures of each State government from all five continents, and must seek a consensus for a resolution, which can be costly and time consuming.

To adapt human rights to regional preconditions, a set of inter-governmental organizations have been established. The U.S is a member of the Organization of American States that represents the American continent (the OAS). This organization adopted a disability-specific treaty a decade before the UN Disability-Specific Treaty was drafted. However, we will not consider it because the U.S. has neither signed nor ratified it in contrast to the majority of other State Parties. An equivalent organization in Europe of which Sweden is a member is the Council of Europe. Sweden is also a member of the European Union (EU), an organization which has certain features that lack any equivalence in other inter-governmental organizations. In contrast to the UN, OAS and the Council of Europe, the EU was not originally established to promote human rights. Instead the original objective was to establish a common market to strengthen Europe to compete in the global market. Europe is characterized by small countries with different legal cultures. It is through economic cooperation that these countries will have better capabilities to compete with other countries like the U.S. and Japan. The EU will also reduce European tension to promote international peace. Later, certain Member States threatened to terminate their membership unless the organizations respect their individual domestic constitutional protections of human rights. To avoid this problem, the organization’s adjudicative body (the EU Court) found that human rights were a principle of general law that the


organization was under a legal duty to obey. Unlike the UN and OAS, neither the Council of Europe nor the EU has adopted a disability-specific treaty with a wide coverage, but some relevant provisions are exclusively designed for persons with disabilities. Therefore, the UN Disability-Specific Treaty, the European treaty collection, and EU legislation will be discussed in detail. The focus is on their objective, personal scope, coverage and enforcement.

3.1 The United Nations Disability-Specific Treaty

Firstly, it should be noted that The UN Disability-Specific Treaty does not create new parameters in human rights, but reaffirms what is already stated in existing treaties on human rights. It should not be interpreted that the UN segregates these human rights for persons with disabilities. Instead, it is up to each person with a disability to rely on this Treaty or other treaties that are available, such as general treaties (e.g. the Bill of Rights) and specific treaties on other vulnerable groups. However, the Disability-Specific Treaty is generally most effective because it confirms existing human rights and tailors them to particular needs that persons with disabilities have. One benefit of this treaty is that it makes human rights for persons with disabilities visible both at the international and domestic plane. Under article 1.1, the purpose of the treaty “is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” This objective should be studied together with the general principles found in Article 3. According to this article, the Treaty is based on respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, personal independence, and equality of opportunity. This Treaty recognizes substantive equality in the sense that persons with disabilities are not considered to be objects of charity, medical treatment and social protection, but as subjects with equal rights and opportunities to others. Therefore, the Treaty recognizes a paradigm of disability models from the medical to social or biopsychosocial model.

To be entitled to treaty protection, a person must be covered by the provisions of the Treaty. According to Art. 1.2, the personal scope includes those “who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” This article should be interpreted through the Preamble, which recalls that the concept of disability is dynamic. Therefore, the Treaty recognizes that the concept is relative and adapts to medical and technological development. Disability can be eliminated through medical care and can appear as a result of development of new diagnosis of symptoms, such as attention deficit disorder during the 1990s. It


53 See generally Sahlin, supra note 1, at 240 – 247 (for a more in depth analysis).

54 The Bill of Rights consists of three parts, i.e. the Universal Declaration of Human Rights, the Covenant on Civil and Political Rights and Covenant on Economic, Social and Cultural Rights. Most important specific treaties are International Convention on the Elimination of All Forms of Racial Discrimination (UNTS I-9464, 1966), the Convention on the Elimination of All Forms of Discrimination Against Women (UNTS I-20378, 1979) and the UN Convention on the Rights of the Child (I-27531, 1989).

55 CRPD, supra note 40, art. 1.1, art. 3.

56 See supra Part 1 (economic equality is a special form of substantive equality).

57 See supra Part 2.1.1.

58 CRPD, supra note 40, art. 1.2.

59 CRPD pmbl. § e.
should be noted that the Article explicitly uses the word “include” to identify the dynamic nature of personal scope. As a consequence, it is up to the State to widen the personal scope to cover all persons, but it must not exclude those who are explicitly found in the Treaty provision. Such an approach is a result of a compromise between those state delegations that favored a universal definition – biopsychosocial model of disability – and others who favored a more restrictive definition – medical model of disability – during the Treaty making process. One problem is that neither the Treaty nor interpretive material clarifies the duration criterion “long-term”, which limits the State’s minimum duty. Therefore, it is unclear when a disability is considered to be temporary, thus liberating the State from its duty. However, the State should not interpret the duration criterion too narrowly to evade its duty, but should consider an assessment similar to the UN’s assessment. The UN has determined that 10 percent of the world’s population is disabled, 80 percent of which live in the developing world, a number equal to approximately 650 million people.

To attain the Treaty objective, the State must adopt all appropriate legislative, administrative and other measures. The State is entitled to choose a measure that is most appropriate in accordance with its legal culture. However, if a certain measure is not effective, then the State must create a more effective measure. Therefore, a legislative measure may be necessary to correct ineffective administrative policy. Regardless of which measure is chosen, it must cover all categories of human rights that the Treaty protects, including civil, political, economic, social and cultural rights. The right to adequate standards of living and social protection includes the right to compensation. According to this article, the State agrees to “take appropriate steps to safeguard and promote the realization of this right... to ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State [Party] with disability-related expenses including... financial assistance.” The Treaty does not clarify the concept of extra cost (“disability-related expenses”). However, it should be noted that extra costs are linked to “situations of poverty” for persons with disabilities. The Treaty does not prevent the State from removing this link because it is a minimum standard. The State is also entitled to provide stronger protection than what the Treaty offers. The Treaty recognizes that such a protection for persons with disabilities does constitute discrimination. Therefore, the question remains as to what is required so that the State attains this minimum standard.

Some guidance is provided by the Preamble, which determines that the majority of persons with disabilities live in conditions of poverty and that poverty has a negative impact on them (Rec. t). It is unclear with whom a person with a disability should be compared. There are two interpretations of the Preamble. One interpretation is objective in the sense that a person with a disability is considered to be poor as soon as his or her total income is below subsistence level that the State Party determines for its own citizens irrespective of disability. The second interpretation is subjective in the

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60 Kanter, supra note 25, at 291-292.
62 CRPD art. 4.
63 Id. at art. 28.
64 Id. at art. 28.2 c.
65 Id. at art. 5.4.
66 Cf. the World Bank statistics, supra Part 1; CRPD pmbl. § f.
sense that a person with a disability is considered to be poor as soon as his or her disability has a negative effect on his or her total household budget. The comparison is based on a general assumption about how the person’s household budget would have looked if he or she had a disability.67 The latter interpretation is based on the UN Standard Rules on Equalization of Opportunities for persons with disabilities, to which the Preamble refers.68 These Standard Rules contain one provision that states that the State Party should ensure that persons with disabilities get sufficient financial assistance to compensate their income loss and that other types of extra costs are also considered (Rule 8). Neither the Treaty nor the Standard Rules explicitly state which forms of compensation measures should be chosen, but the State should choose a measure that is most effective to attain the Treaty objective. This should include all types of extra costs.

Apart from this interpretation problem, the right to compensation is also identified as a social right,69 which constitutes a special duty for the State. Under article 4.2 the State “undertakes to take measures to the maximum of its available resources... with a view to achieving progressively the full realization of [social] rights.” 70 This article lacks of a particular guidance and originated in the U.N. Covenant on Economic, Social and Cultural Rights.71 The U.N. Committee on Economic, Social and Cultural Rights has issued a guide to interpreting this article.72 The use of “progressively” should not be interpreted as if the State is entitled to postpone its duty to an indeterminate date in the future, but rather to establish a necessary flexibility plan that reflects actual circumstances and difficulties experienced within the State. However, certain discrimination prohibition measures should be implemented immediately to establish eligibility criteria for a compensation scheme. The expression “to the maximum of its available resources” should be interpreted as the State ensuring the respect of minimum subsistence rights for all persons. All Treaty rights must not be neglected. The Preamble of the Treaty prescribes that all rights are universal, indivisible, interrelated, interdependent and equally important; therefore, the right to an adequate standard of living is ranked equally with other rights such as awareness-raising, accessibility, habilitation and rehabilitation.73

As soon as this minimum standard level is attained, the question is how the State should redistribute its available resources to satisfy disability needs. According to the Preamble, the State must give priority to the most vulnerable groups such as people with severe disabilities, women with disabilities, and children with disabilities.74 This choice is based on the fact that the UN, through other specific treaties, recognizes that many women and children suffer from double discrimination compared with other disabled groups such as exploited children and gender-based discrimination. One problem is that the Treaty does not deal with other groups of persons with disabilities such as persons seeking asylum and indigenous people; however, other treaties specific to their particular

67 See supra Part 2.2 (about the comparative method).
68 CRPD pmbl. § f.
69 See supra Part 3.
70 CRPD, supra note 40, art. 4.2.
71 CESCR, supra note 2, art. 2.1
73 CRPD, supra note 40, art. 8-9, art. 26.
74 Id. at art. 6-7; CRPD pmbl. § j.
disabilities may cover these persons. To secure that this right is upheld, the State has a duty to ensure that a person with a disability has effective access to justice equally to others. Such a right requires that judges have enough training to understand the living conditions of persons with disabilities.

To enforce the Treaty obligation, the State is under a legal duty to submit a legal report to the Committee on the Rights of Persons with Disabilities. This committee, which consists of independent disability experts from all five continents, is empowered to assess whether or not the State violates the Treaty. In contrast to the U.S., Sweden has ratified an optional protocol which empowers the committee to consider individual complaint. A person must first have exhausted all domestic measures before submitting such a complaint. The committee is not authorized to impose sanctions on the State to obey its Treaty obligations. Instead, the monitoring system is based on the presumption that the State is morally or politically willing to cooperate. However, it is problematic for Sweden, which takes a dualistic view of its international obligations. The Treaty is regarded as an international law apart from Swedish law. A person cannot invoke international law before a domestic agency or court unless the Treaty is either transformed or incorporated into Swedish law. Sweden has chosen not to implement the Treaty into Swedish law. The only way for a person with a disability to invoke international law is to argue that Swedish agencies and courts should interpret Swedish law in the light of the Treaty, also called a treaty-conform interpretation.

A review of the case law shows that the Committee at present has only considered an individual complaint against Sweden in H.M. Although this complaint did not deal with the Swedish compensation scheme but the Swedish Planning and Building Act, it provides good representation of the attitudes Swedish judges have towards persons with disabilities. In this complaint, a woman with a neuromuscular impairment – Ehlers-Danlos Syndrome – requested an exemption from the prohibition on building under a development plan that the Swedish municipality issued. Her disability required a hydrotherapy pool in her property. There was no alternative habilitation and rehabilitation because she could not leave her house due to a high risk of infection and mobility constraints. The Swedish Administrative Court of Appeal found that there was no legal possibility to make an exception from the development plan for her disability. The Swedish Supreme Court refused to review this decision. During the proceedings before the Committee, Sweden argued that Swedish laws did not discriminate against persons with disabilities and that judgments delivered by domestic authorities were not motivated by the woman’s disability. The Committee found that Sweden violated the principle of equality and non-discrimination in conjunction with some substantive rights including habilitation and rehabilitation. According to the Committee Sweden had not argued that an

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76 CRPD, supra note 40, art. 3.1.
77 Id. at art. 13.2.
78 Id. At art. 34-39.
80 It can be compared with the U.S., which has a mixed monist-dualist system. This means that international law directly applies in U.S. courts in some instances but not others.
exemption from the developmental plan would impose a “disproportionate or undue burden.”

Therefore, the Committee emphasized that the principle of non-equality and non-discrimination should be based on a proportionality test and substantive equality.

3.2 European Treaty Collection

The Council of Europe has revised its European Social Charter (1996) so that it not only includes employment rights, but also other social rights such as social security (Art. 12), social and medical assistance (Art. 13), and specific rights for certain vulnerable groups including persons with disabilities. A disability-specific provision entitled “the right to independence, social integration and participation in the life of the community” is found in Art. 15. Under this article, the State undertakes the promotion of “full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure.” The question is whether the article should be interpreted to implicitly include a compensation scheme. An authoritative guidance states that the Treaty should be interpreted in the light of a non-legally binding recommendation, which explicitly states that the State should provide effective protection to persons with disabilities, with an aim to develop their social and economic integration.

Sweden has ratified a protocol to empower the European committee on Social Rights – a treaty-monitoring body consisting of independent experts – only to consider collective complaints. A person with a disability must contact any non-governmental organization to represent him or her before the committee. One requirement is that this non-governmental organization has a consultative status according to the Council of Europe's approved list of organizations, including the European Disability Forum and International Autism. Like the UN’s disability-specific committee, the Swedish committee does not have any sanction power to oblige the State to obey the Treaty. To ensure that there is no conflict between these committees, they will not consider a complaint that deals with the same issue. Therefore, the individual or its non-governmental organization may choose only one of these committees. Case law shows that the committee on Social Rights has interpreted the disability-specific provision in the light of the WHO’s ICF and the UN Disability-Specific Treaty. According to the committee, a compensation scheme can be an effective means of promoting social integration. Although the Treaty does not have any provision that instructs the State as to how to redistribute its available resources equally to the UN Disability-Specific Treaty, it can be argued that

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82 Id.
83 Council of Europe, European Social Charter (Revised), May 3, 1996, ETS 163; see generally Sahlin, supra note 1, at 247-251 (for a more in depth analysis).
84 CRPD, supra note 40, art. 12-13.15.
the committee should assume responsibility for this provision. Nevertheless, the Committee has found that Swedish domestic law is compatible with the Treaty provision.\textsuperscript{89} In this context, it should be noted that the committee view did not come from an individual complaint but from periodic reports which Sweden is obliged to send as a result of the Treaty obligation.

A person with a disability who wishes to file an individual complaint without any assistance from a non-governmental organization can rely on another treaty: \textit{the European Convention on Human Rights}.\textsuperscript{90} \textit{The European Court of human rights} is empowered to order a violating State Party to pay damages to the complainant. It is the most powerful treaty of all existing international treaties. To avoid dualistic problems, Sweden has incorporated the Treaty into Swedish Law. Although the Treaty only deals with civil and political rights, there is a relevant provision that is notable. Under article 6, a person has the right to “a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law.”\textsuperscript{91} This requires that a person’s civil rights be violated. The case law shows that the Court has interpreted the concept of civil rights broadly so that it encompasses the right to childcare and disability benefits, which is included in the Swedish compensation scheme.\textsuperscript{92} This is necessary for Sweden to ensure that persons with disabilities have effective legal measures to claim their legal right to a certain form of compensation, such as access to a hearing and legal aid to finance their legal representation.\textsuperscript{93}

### 3.3 EU Legislation

The EU has ratified the UN Disability-Specific Treaty;\textsuperscript{94} however, despite the fact that the EU Constitutional Treaty authorizes the EU to ratify the European Convention on Human Rights, it has chosen not to do so.\textsuperscript{95} Instead, the Constitutional Treaty recognizes that the European Convention is included as a general principle of law. As for the disability-specific provision in the Revised European Social Charter, the EU has introduced an equivalent provision in its own Bill of Rights: \textit{article 26 Charter of Fundamental Rights (2000)}.\textsuperscript{96} According to this article, persons with disabilities have the right to “benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.” This Charter was incorporated into the Constitutional Treaty in 2009 through the Lisbon Treaty.\textsuperscript{97} Furthermore, the Constitutional Treaty states that the goal of the EU’s social policy is to create an adequate social protection that is equivalent to that of the Revised European Social Charter.\textsuperscript{98} The main idea is to secure that EU

\begin{itemize}
  \item \textsuperscript{89} See European Committee of Social Rights Conclusions 2012, (Swed.), art. 15 -2, December 11, 2012.
  \item \textsuperscript{91} CRPD, supra note 40, art. 6.
  \item \textsuperscript{92} See, e.g., \textit{Lundevall v. Sweden}, Complaint No. 38629/97, November 11, 2012; see also \textit{Salomonsson v. Sweden}, Complaint No. 38978/97, November 11, 2012; See infra Part 4.2.
  \item \textsuperscript{93} See infra Part 4.2.
  \item \textsuperscript{94} Council Decision (EC), No. 48/2010 of 26 November 2009, 23 O.J. 35; see also Sahlin supra note 1, at 251 -257 (for a more in depth analysis).
  \item \textsuperscript{95} European Union Constitutional Treaty art. 6.2, June 2004, 310 E.U.T.S. 01 (hereinafter TEU).
  \item \textsuperscript{96} European Union Charter of Fundamental Rights art. 26, 2000., 364 E.U.T.S 01.
  \item \textsuperscript{97} TEU, supra note 89, art. 6.1.
  \item \textsuperscript{98} Id. at art. 151.
\end{itemize}
legislation is compatible with international treaties on human rights. However, a person with a disability cannot challenge a State Party that violates any international treaty before the EU Court. The EU is not authorized to impose a legal duty on the State Party to establish or develop a compensation scheme that is financed with tax revenue. This issue is considered a matter of the State Party’s sovereignty. The competency of the EU is dictated in the Constitutional Treaty (e.g. Art. 4 and 5 TFEU). There is one competency issue that is relevant, which is *discrimination prohibition*. The EU is competent to prohibit a host State Party from discrimination, irrespective of disability, because of a person’s nationality. For instance, Sweden is obliged to treat a person with a disability from Italy equally to a person with a disability from Swedish in respect of eligibility criteria for a certain form of compensation. This national discrimination prohibition is used as a necessary means of promoting economic integration within the establishment of an internal market without any national barriers in respect of persons, goods, services and capital. This is included in the Treaty objective to promote the economic integration at the Union market.

Since the Amsterdam Treaty entered into force in 1999, the EU is competent to take effective measures that prohibit the State Parties from discriminating against persons on the grounds of disability. The Commission – the executive body – has utilized this competency to submit a proposal for a directive on discrimination prohibition for disability within a set of social areas including social security and insurance. The proposal, which is a minimum standard, will not impose a legal duty on the Member State to establish or develop a domestic compensation scheme, but rather to interpret eligibility criteria on an equal basis for all social insurers, irrespective of disability. It will probably not prevent a Member State from creating or developing its disability benefits that compensate extra costs for certain groups of persons with disabilities without violating the proportionality principle. This discrimination prohibition must be enforced through effective legal remedies. If the Council of Ministers (the legislative body) adopts this proposal, the State Party will be obliged to transpose the directive into its respective domestic legal order. However, the State Party would be allowed to choose which form and means to implement the directive according to its legal culture. Therefore, the legislation in the U.K. does not need to be drafted in similarly to Sweden. A State Party that neglects to transpose it can be ordered to pay damages to a person with a disability who is disfavored. However, this person may only file a suit before a domestic court, not the

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100 TFEU, supra note 89, art. 4-5.

101 It can be noted that the treaty includes an additional provision that states that the EU shall aim to combat discrimination based on disability in defining and implementing its policies and activities (Art. 10 TFEU); TFEU, supra note 93, art. 18.

102 See infra Part 4.2 (about the insurance affiliation)

103 TFEU, supra note 89, art. 4.

104 See supra Part 4.

105 TFEU, supra note 93, art. 19.


108 TFEU, supra note 93, art. 288.3.
EU Court. If any EU rule is unclear, the domestic court is under certain circumstances obliged to request that the EU Court issues a preliminary ruling on how to interpret EU law. The basic idea is for the EU Court to focus on general principles and for the State Party court to focus on concrete issues. Although the proposal has not been adopted, case law shows that the EU Court has interpreted the anti-discrimination Directive in regards to employment in light of the UN Disability-Specific Treaty. These cases dealt with the concept of disability that the directive does not define. To avoid a dualistic problem, Sweden amended its Swedish prior to its EU membership in 1995. According to the Constitution, Sweden has made an exception to give EU legislative priority to Swedish domestic law.

4 Domestic Compensation Schemes

Neither the U.S. nor Sweden has established a compensation scheme that is exclusively designed to compensate all types of extra costs that persons with disabilities may incur. Instead, the core of their domestic compensation schemes is found in the U.S. Social Security Disability Insurance Program and the Swedish Social Insurance Program. History shows that these programs were not established as a result of international duties, described in the previous section. Instead, they were established in response to a shift in public attitudes. Classical liberalism had a great impact on the U.S. Social Security Disability Insurance Program. The U.S. is the last country to introduce the program amongst all industrialized countries. According to Esping-Andersen, the U.S. approach is identified as a liberal welfare system. By contrast, Sweden is considered to have the world’s oldest program, and it is identified by Esping-Andersen as a social democratic welfare system. To understand to what extent persons with disabilities can rely on these programs and to what extent these programs are supplemented by other forms of compensation, we will use the following comparative data: historical background, ideological purpose, personal scope, coverage and enforcement. Due to the countries’ ideological differences, the domestic compensation schemes will be addressed separately. This means that we will first emphasize some major features of the U.S. approach and later focus on the extent to which the Swedish approach differs from the U.S. approach.

4.1 The U.S Approach

Classical liberalism in the U.S. originated during the American Revolution, which liberated the U.S. (then 13 colonies) from the British Empire in 1776. At that time, Congress proclaimed that the U.S. was a sovereign state through a historical document: the Declaration of Independence. This Declaration contains fundamental concepts “life, liberty and the pursuit of Happiness” which has a strong affect American attitudes toward the relationship between the state (federalist versus state government) and the citizenry irrespective of disability. This attitude dictates that state intervention should be minimal in the sense that all Americans should be entitled to develop their fullest potential


110 See supra 2.1.2 and 2.1.3.


113 Id. (explaining that the concept of social democracy has its origin in Sweden’s largest political party that governed Sweden for many decades during the 2000s).

114 See supra Part 1.
in a free and open economic market.\textsuperscript{115} Such state intervention should merely secure individual autonomy and promote social development in the U.S. However, during the Great Depression, Americans began to realize that some degree of state intervention was necessary to protect them against poverty.\textsuperscript{116} This shift of public attitudes enabled President Franklin D. Roosevelt to establish a financial reform program, so called the New Deal. As a result of this program, Congress in 1935 enacted the Social Security Act to provide benefits to compensate income loss for survivors, retirees, dependent widows and children with a single parent. The U.S. Supreme Court of Justice held that Congress did not exceed its authority in violation of the Constitution of the U.S.\textsuperscript{117} According to the Court, the Act was a mere exercise of Congress’s general taxation powers. Although President Roosevelt proposed that the Act also should include persons with disabilities, Congress denied the proposal for fiscal reasons.\textsuperscript{118}

After years of lobbying, the time was right for Congress to enact disability-specific benefits for workers with disabilities in 1956, i.e. \textit{Social Security Disability Insurance} (SSDI). One precondition was that a person had to be aged 50 to 64 years and had to have a disability that was either deadly or total and permanent. The lower age limit was removed in 1960. Later during the 1960s, the concept of disability was expanded to cover disabilities that are expected to last at least one year (1965). A particular benefit for those who had no work history and low income or resources was introduced in 1973, i.e. \textit{Supplemental Social Security} (SSI). The last important reform came in 1984, when the concept of disability was amended. One main objective was to liberalize the disability screening progress to enable persons with low mortality disorders such as back pain, arthritis and mental illness to qualify for disability benefits.

Statistics show about 80 percent of working-age American adults are insured against the risk of being unable to work because of disability through the Social Security Disability Insurance program.\textsuperscript{119} Further statistics show that 8.8 million American workers with disabilities receive SSDI, and an additional 3.2 million impoverished Americans with severe disabilities receive SSI. Taken in conjunction with the UN’s assessment that 10 per cent persons with disabilities live in industrialized countries, there should be more than 31 million persons with disabilities in the U.S. (the total U.S. population is 313.9 million).

Congress has utilized the \textit{Social Security Trust Fund} to collect payroll taxes to finance the SSDI.\textsuperscript{120} The amount of taxes that must be collected is a matter for Congress to determine. In contrast to the UN Disability-Specific Treaty, there is no constitutional provision that obliges Congress to regulate

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  \item \textsuperscript{115} See supra Part 2.3.
  \item \textsuperscript{117} See Helvering \textit{v. Davis}, 301 U.S. 619 (1937); Steward Machine Company \textit{v. Davis}, 301 U.S. 54, 8 (1937) (affirming the constitutionality of the program by the Supreme Court of the U.S.); see also Helen F. Ladd & Fred C. Doolittle, \textit{Which Level of Government should assist the poor?}, XXXV National Tax Journal, at 323 – 336 (1982).
  \item \textsuperscript{118} See Stone, supra note 16, at 70.
  \item \textsuperscript{120} Official Social Security Website, Social Security Administration, http://www.socialsecurity.gov.
\end{itemize}
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available resources (tax income) to be distributed to persons with disabilities. It is not the Social Security Trust but rather the Social Security Administration (SSA) that is entrusted to administer eligibility criteria of the program. This agency has issued a set of regulations to facilitate the interpretation of the Act. Persons with disabilities cannot go to this agency to apply for benefits, but will rather be directed to local social security administration field offices that exists in each state (LSA). This agency investigates whether a person satisfies eligibility criteria to get SSDI or SSI. Firstly, a person must reside legally in the U.S. at least 12 months to apply for the SSDI or SSI. It does not matter whether the person has an American citizenship or not; rather, the purpose is to exclude those who are tourists from taking advantage of the tax-financed program or to prevent American citizens overseas from taking advantage of equivalent programs overseas simultaneously. Another non-medical criterion is age, which is different based on benefit type. A person must be below the age of 65 to claim the SSDI or he or she is addressed to another benefit for elderly persons. Such an age limit does not exist for the SSI.

A third non-medical criterion is that a person must provide work history to claim the SSDI. The length of work experience varies depending on the person’s age. Generally the person must have accumulated 20 social security credits in the last ten years prior to the onset of disability (normally four credits per year). This is not required of persons who can show that they received disability before the age of 20. Instead, persons can collect on their parent’s work credits. By contrast, the SSI is income and means tested, which means that a person must show that his or her income and resources fall below the poverty line that the U.S. Department of Health & Human Services issues each year. A person must remain at this threshold, otherwise he or she will no longer be entitled to the benefit. As the benefit is a last resort, a person must first apply for another benefit, with one exception being certain in-kind programs that will be discussed below. In this context, there are some special provisions for those who are “legally visually impaired.” It would be complex to emphasize the special feature of these provisions, such as definition of blindness, financial situation and simplification of administrative procedure. Therefore, We will not consider these special provisions in this article.

The Disability Determination Service (DDS) assesses the medical criterion that a person must satisfy to get the SSDI or SSI. A person must undergo a screening procedure. The agency first examines whether a person has a disability that makes him or her “unable to engage in substantial gainful activity (SGA). A person who passes this test must also have a disability that is expected to last at least one year. If the person has a disability that is found in a listing of disabilities, he or she does not need further assessment. Such a listing covers typical diagnoses such deafness, musculoskeletal problems, skin disorders and cancer. Otherwise, a person must prove that his or her disability has a residual functional capacity. This assessment also considers a person’s age, previous relevant work, and education to determine his or her ability to perform work generally available in the national economy. This performance is assessed at five levels of work: sedentary, light, medium, heavy and very heavy. A person who argues that he or she has pain will only be considered provided that his or her disability is diagnosed.

A person who satisfies all eligibility criteria will get a monthly payment, which can be given on a permanent or temporary basis. The payment amount is different for the benefits, which aim at

121 See supra Part 3.1.
122 20 C.F.R. § 404.1615.
compensating income loss for persons with disabilities (indirect cost). The calculation is very complex, but the SSDI is primarily based on a person’s earlier annual work average income while the SSI is a minimum standard that is adapted to the financial situation of persons with disabilities depending on the household size.

Both benefits entitle persons to apply for some in-kind programs that are federally sponsored. One is health and medical insurance to which persons with disabilities are automatically entitled, i.e. Medicare for SSDI beneficiaries after two years, and Medicaid for SSI beneficiaries immediately. To promote those who have SSI to look for a job, President Clinton established a program that secures that they will not lose Medicaid, the so-called Ticket-to-job-program. Those who have financial difficulty purchasing food can apply for federal sponsored food programs that states administer, called the Supplemental Nutrition Assistance Program (SNAP, earlier known as food stamp). This program considers extra costs that persons with disabilities incur because of food. Since these financial programs are a minimum standard, there is nothing to prevent all 50 states, local governments and non-profit organizations from establishing financial programs that supplement the federal programs such as shelter, tax credits and concessions. These actors are entitled to establish their own eligibility criteria for this supplement.

To enforce the benefits, there is a four-state administrative procedure, which requires: 1) reconsideration by a different examiner from the state DDA office, 2) a hearing before an Administrative Law Judge (ALJ), 3) a review before the Appeals Council and 4) filing suit against the SSA in U.S. district court. At each stage of the appeals process, a claimant must request an appeal to the next level within 60 days of receiving a notice of the prior decision. SSA is not represented at the hearing before the ALJ, but rather before district court. Therefore the ALJ hearing is considered to be inquisitorial while the U.S district court is adversarial. There is some congressional debate as to whether the ALJ should be adversarial to make the ALJ more impartial. Persons with disabilities may access legal representation to argue for their applications or appeals. There are two types of organizations that can help a person with a disability to apply or appeal a decision. One is companies with trained specialists experienced in handling applications and appeals across the country, and the other is law firms that specialize in disability-related cases. The fee which a representative can charge for the benefit is set by law. Currently, under the fee agreement approval process, this fee is 25 percent of the retroactive dollar amount awarded. A person with a disability is not required to pay for this fee. Disability representatives do not charge a fee if they are unsuccessful in obtaining a benefit. If the application is approved without a retroactive award, the SSA must review and approve the fee. However, a representative is entitled to decline to represent a person with a disability if he or she does not believe that the person is likely to satisfy the eligibility criteria. They provide a screening at no cost for the person. This system is fairly successful,

123 See Patient Protection and Affordable Act of 2010, Pub. L. No. 111-148 (codified as 42 U.S.C. § 300gg et seq.) (will enter into force in January 2014. This Act will provide health insurance to approximately 45 million Americans who currently are without any protection).


with statistics showing that about 90 percent of persons with disabilities have legal representation before each state.\(^{126}\)

### 4.2 The Swedish Approach

First, it can be noted that classical liberalism has also been the dominant ideology in Sweden.\(^{127}\) Until the mid 1900s, persons with disabilities relied on their relatives and other benefactors for their survival. Disability constituted a legitimate ground of begging to distinguish them from others who were considered malingerers. This ideology was gradually weakened during the 1900s. At that time, Sweden underwent rapid industrialization and urbanization, where the majority of Swedes gradually left their farms for a better life in larger, industrialized cities. However, their expectations were often unrealistic, and employers were able to exploit them. Many employees risked their lives for minimal pay. Such miserable employment conditions spurred them to strike and demonstrate for better employment protection. This struggle had a great impact on the Swedish Parliament to abandon classical liberalism for social solidarity. Already in 1913, Parliament enacted the Pension Act, which is considered to be the world’s oldest social insurance plan. This act included two social insurance benefits – the old-age benefit and the invalid benefit – that compensated income loss for persons who could not work due to age of retirement or disability, respectively. Already during the same decade – the 1910s – visually impaired activists criticized the invalid pension for not considering extra costs. In 1934 after much lobbying, a specific benefit was introduced to be exclusively designed to satisfy special needs for visually impaired adults. This benefit compensated income loss, care needs and extra costs. A person with a visual impairment was not required to show work history because they were considered unable to be self-sufficient. About a decade later, the benefit was divided into a visually impaired pension to compensate income loss and a non-income-tested visually impaired addition to compensate care needs and extra costs.

Ten years later, persons with severe disabilities received an equivalent benefit, i.e. invalid pension and invalid addition. In the mid 1960s, a childcare benefit was introduced to facilitate children with disabilities to leave institutions and hospitals to live with their families. This benefit was considered to be a necessary means to promote the principle of normality and integration that was newly introduced at this time. Benefits and additions were merged with childcare and disability benefits during the mid 1970s. The main goal was to make the benefits more accessible to laypersons. Legislators began questioning the paradigm of disability models, which occurred during the 1970s and 1980s in Sweden, whether childcare and disability benefits had any raison d’être. In other words, whether the benefits were compatible with the social model of disability. After having investigated this question, the government found that the benefits were a necessary means to promote economic equality.\(^{128}\) During the early 2000s the invalid pension was divided into activity and sick benefits to emphasize that the benefit is not lifelong, and to encourage persons with disabilities, particularly those who are young, to work.\(^{129}\) This benefit was expected to promote the employment principle in


\(^{127}\) See generally Sahlin, supra note 1, at 51-66 (for a more in depth analysis of disability history).


the sense that resources should be redistributed to cover costs for measures to facilitate persons to work instead of remaining stagnant.

There are currently four specific benefits that are adapted to compensate extra costs for persons with disabilities: activity benefits, sick benefits, childcare benefits and disability benefits. Statistics show that of the 486,085 persons with disabilities who received benefits in 2012, 377,865 received activity or sick benefits, 46,492 received childcare benefits, and 61,728 received disability benefits. These data reflect that of the more than 9 million persons living in Sweden, only a small group of persons with disabilities receive benefits, and especially disability benefits.

These benefits are financed through tax collection administered by the Swedish Tax Agency. The Swedish Parliament has the sole power to determine how much tax money should be spent to finance the four disability-related benefits. One exception is that Sweden is under a legal duty to respect the EU Convergence criterion. The objective is to ensure that no State Party, including Sweden, has an excessive budget deficit that can have a negative affect the European financial market.

The National Social Insurance Agency is the sole administrative agency for benefits. In contrast to the U.S., there is no binary legal system, but rather a unitary one. The benefits are regulated in the Social Insurance Act of 2010 that merged multiple older social insurance acts. The purpose is to make the complex social insurance system more accessible to laypersons. There is no equivalent to the U.S. code of regulations that facilitates an interpretation of the act. Instead, the agency has issued non-legally binding guidance on the benefits that the court approves. Legislative preparatory works are the most important means of interpretation in Sweden. It This special branch of the Civil Law system is typical of the Scandinavian Legal System and can be found in a couple of European countries such as France and Germany. There is a belief that the law should be interpreted as far as intention of legislators is a true reflection of democratic willingness, which means courts should take a restrained approach.

As in the U.S., a person must be covered by the Swedish social insurance affiliation. All four benefits are resident-based in that a person must reside in Sweden for at least one year. To make sure that the residence criterion does not violate the EU discrimination prohibition on the grounds of nationality, citizens from other EU countries are qualified provided that they work in Sweden even though they reside in other State Parties. This is profitable for such citizens because Sweden

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130 Forsakringskassan (Social Insurance Agency), http://www.forsakringskassan.se (statistics).
131 See supra Part 4.1.
133 TFEU, supra note 93, art. 119-144.
134 Försäkringskassan (Social Insurance Agency), http://www.forsakringskassan.se.
137 See generally Sahlin, supra note 1 at 77 -83 (for a more in depth analysis of the insurance affiliation).
139 See supra Part 3.3.
provides the most generous benefits in the EU. If the activity and sick benefits are based on the person's earlier income, they are work-based. As soon as persons are covered by this affiliation, they must satisfy additional eligibility criteria, which are different depending on benefit.

A person must satisfy an age criterion for all the benefits. There is a lower age limit for the activity benefit that is adapted to the age where young persons are expected to complete secondary education, i.e. the age of 19 years. The upper age limit is set to the lower age limit for sick benefit, i.e. 30 years. The main objective of this criterion is to oblige the agency to find an activity that a person can partake in and that has a favorable effect on his or her disability. It is necessary to do everything possible to prevent young people from stagnating for the remainder of their lives. The upper age limit is adapted to the general age of retirement, i.e. 65 years.

The age of 19 is a determinate division between childcare and disability benefits. Parents or guardians of children with disabilities are entitled to apply for childcare benefits. If they are separated or divorced, they can request that the benefits be divided between them. There is no lower age limit for childcare benefits. Case law shows that some diagnoses qualify a child to be entitled at birth. The reason is that parents have as much need of support to finance extra costs for children with disabilities such as Downs Syndrome, hearing loss, and visual impairment. There is an upper age-limit on the general age of retirement, i.e. 65 years. This is fixed to the general age of retirement so that that elderly receive old care benefits. Otherwise, it would be a financial burden on the state because disabilities such as brittleness of the bones and senile dementia are associated with old age. It should not be interpreted that a person who has a benefit prior to the age of 65 will lose it. The age limit is only for those who claim a new benefit. Case law further suggests that the court is very strict. If a measure is invented after a person has turned 65 years, he or she cannot claim that this cost should be approved as an extra cost although their disability is unchanged. According to the court, the person did not have such a cost before the age limit.

If a person has satisfied all non-medical criteria for a certain benefit, the agency will further assess whether he or she must also satisfy the medical criterion or disability. In contrast to the U.S., the same agency in Sweden makes such an assessment. Although the concept of disability is not defined in the act, it covers all types of disabilities; however, severity and duration vary depending on benefit type. A disability must last at least one year for all three benefits except for childcare benefits, where the duration is shortened to six months. One reason for this stipulation is that it is more difficult to predict the final medical state of a child than an adult because children continue to develop. The burden of proof is high for activity and sick benefits, and there must be a determinate causal link between a disability and reduced work capability, the minimum level of which is a 25 percent reduction in work capability. This assessment is based on a person’s ability to make his or her own living in the labor market based on his or her own knowledge, experience and interest. A similar link is required for childcare and disability benefits in that there must be a determinate causal link between a person’s disability and any extra cost or particular care need.

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140 See generally Sahlin, supra note 1, at 83-86 (for a more in depth analysis about age criterion).


142 See generally Sahlin, supra note 1, at 86-102 (for a more in depth analysis regarding child care and sick benefits).
The act does not clarify the concept of extra costs and care needs. The government is reconsidering removing the care need criterion because it is outdated. Such needs are often satisfied through a set of legal measures that were introduced during the 1990s, such as personal assistance and sign language interpretation. Such measures were underdeveloped when the childcare and disability benefits were introduced in the 1970s; therefore, the cost is generally the most relevant. Some guidance from legislative preparatory works that is an important means of interpretation in Sweden is available. According to these preparatory works, indirect costs such as income loss cannot be approved as extra costs because the statutory text is not drafted in this way; however, a person may be directed to rely on activity benefits or sick benefits in this case. One problem is that there is no benefit to compensating income loss below the minimum level (25 percent). It is possible that a worker with a disability needs to forego a few hours of work to visit his or her physician. Moreover, the preparatory work shows that potential costs can be approved as an extra cost. This occurred during the 1970s to prevent only those who could afford to cover their costs from getting benefits.

Regarding opportunity costs, Swedish case law shows that it is very difficult for a person with a disability to claim that these costs should be approved as extra costs. The benefit is used as a last resort in the sense that a person with a disability must do his or her best to avoid such a cost by applying for targeted support and service measures for which other public entities have a primary duty. For example, a woman with mobility impairment claimed that a housing adaptation should compensate her extra cost so that she could use the restroom on the second floor of a house. The court assessed that the woman should accept that the municipalities adapted the first floor for restroom access. Sometimes the court can interpret this requirement very strictly, which can have a negative consequence for a person with a disability. For example, a man with a gastric disability could not claim a cost for train transportation between his workplace and home because the subway was cheaper. His argument that he needed access to a restroom for his gastric problems was unsuccessful. The court assessed that the man should use a diaper to manage the subway transportation.

If a person has an imperceptible, controversial or psychiatric disability, the risk is that he or she has greater difficulties convincing the agency and court that there is a causal link between them and a claimed cost. The case law shows that the agency or court assesses that the person is exaggerating this link if they lack enough medical evidence. For example, the court generally denies a claim from a person with an allergy to compensate his or her extra costs to sanitize a car or house. The problem is that most judges lack particular knowledge of living experience for these persons, so they have difficulties understanding their claimed costs. Another problem is that it is very difficult for most

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143 See generally Sahlin supra note 1, at 109 -196 (for a more in-depth analysis about the case-law).


145 Id. at 55 -56.

146 See supra Part 2.1.2.

147 Kammarrätten i Jönköping KRNJ 2005-04-12 case (2238-03) [Swedish Administrative Appellation Court in Jönköping April 12, 2005 case no. 2238-03, Swed.].

148 Försäkringsöverdomstolen 1991-12-17 (920-90), [Swedish Insurance Supreme Court December 17, 1991, case no. 920-90] The court was replaced by the Swedish Administrative Supreme Court in 1995.

persons with disabilities to argue that some of their recurring costs are higher than what the Consumer Agency’s surveys show on certain types of household bills for the general population, such as food, electricity and clothes. For instance, persons who have food allergies can show through medical statements that they can only buy certain food items that are more expensive than general food items.

To facilitate a person with a hearing or visual impairment getting a certain level of disability benefit, policymakers have given them preferential treatment in relation to other groups of persons with disabilities. They are not required to argue a causal link between disability and a claimed cost but only to submit medical evidence to prove that the disability is durable and severe. When they have provided a medical statement that certifies their hearing or visibility impairment, they will automatically receive the benefit, which is called a guaranteed disability benefit. This has caused some tension between them and other groups of persons with disabilities that claimed a similar treatment. Policymakers have often denied this claim because they assessed that it is not as easy to determine the boundary of each disability on an objective basis as it is for certain disabilities such as hearing and visual impairment.

As soon as a person has satisfied all eligibility criteria, each benefit can be provided monthly on a temporary or permanent basis. There are different levels depending on the size of work incapability, extra costs and care needs. All these benefits qualify a person to be entitled to get a disability card. Some county councils and municipalities offer disability discounts for local transportation, sports activities, and museums on a voluntary basis. Also, some private entities such as grocery stores may offer disability discounts on goods. A disability is generally considered grounds to justify structural barriers that persons with disabilities face in society irrespective of whether their extra costs are already compensated through benefits.

A person who disagrees with a decision is entitled to have their claim reviewed by another team at the agency, similarly to the appeals system in the U.S. The period of appeal is also similar, i.e. two months. If the agency does not change its decision according to the demand, then it is forwarded to a local administrative court. Like the U.S., Sweden has a three-instance court system whose judgment can be appealed to higher courts. The court is obliged to actively help parties complete their appeals. This is why legal aid is not generally available to persons with disabilities. This system has been criticized for the lack of balance between a person with a disability and the agency that has access to highly qualified legal assistance. This criticism is based on the fact that the agency has better preconditions to persuade the court to interpret the eligibility criteria in a way that is similar to the agency’s opinion. Judges cannot generally be expected to make a better assessment of the causal link between disability and a certain claimed cost. As a consequence, there is a risk that the court overlooks other arguments for the agency’s arguments. This can be unfair to most persons with disabilities who find that it is very costly to hire legal representation. As a consequence there is almost no law firm that is specialized to help persons with disabilities to claim the benefits.

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150 See generally Sahlin, supra note 1, at 197 -258 (for a more in depth analysis about enforcement).  
151 See supra Part 4.1.  
152 In contrast to the U.S., the Swedish court system is dualistic that is influenced by the Civil Law tradition. It means that there are two parallel courts with different competences, i.e. general court (civil disputes between persons) and administrative court (public disputes between persons and public agencies).  
153 Cf. The U.S. supra 4.1.
5 Concluding Remarks

. We have established a theoretical compensation scheme,\textsuperscript{154} which can be extended or narrowed depending on legislative ideology, ambition and financial priority. With this as a starting point the comparative study has confirmed that ideological difference has a great impact on the legal scope of domestic compensation schemes in the U.S. and Sweden (classical liberalism versus social solidarity). Although neither of these countries have a compensation scheme exclusively designed to cover all types of extra costs, the main part of compensation is found in social security and insurance programs. This study shows that eligibility, coverage and enforcement are generally different. The U.S. social security disability insurance program (SSDI and SSI) is work-based or income-tested, while the Swedish social insurance program (activity benefits, sick benefits, childcare benefits and disability benefits) is need-based. Among others there is no categorical division based on work, income and resources among persons with disabilities who live in Sweden in contrast to the U.S. It is more difficult to compare the coverage in both countries. State programs in the U.S supplement the federal program, which is a minimum standard. Such state programs substantially vary from state to state depending on where a person with a disability lives in the U.S.

A similar problem also exists in Sweden despite the fact that the social insurance program is unitary. This can be explained by the fact that statutory texts on childcare and disability benefits are so vague that practice substantially varies from place to place depending on where a person with a disability lives in the country.\textsuperscript{155} Although the Swedish Administrative Supreme Court is entitled to establish a uniform practice, it is extremely rare that the court reviews the matter. In this context, it should be noted that it is difficult for persons with disabilities to argue that they are entitled to a certain benefit in the absence of legal aid. Most judges do not have enough training to understand living conditions of persons with disabilities. Also in Sweden, some county councils and municipalities supplement the social insurance program with other types of compensation measures in particular circumstances on a voluntary basis.

The question of what extent the U.S. and Swedish compensation schemes are compatible with human rights treaties by which the countries are legally bound is not easily answered. These treaties are a minimum standard and vaguely drafted, giving the U.S. and Sweden a large margin of discretion to choose a strategy that is most suitable to their ideological values.\textsuperscript{156} Although the U.S. and Sweden have declared that their respective domestic legislation and compensation schemes are compatible with these treaties, practical experience paints a different picture of this issue. One issue is that the concept of disability is strongly medically oriented in the U.S. and Swedish compensation schemes although the treaties are based on a mixed model of disability (medical and social). Government agencies and courts require that symptoms are medically recognized to assess whether a person is qualified for a certain benefit. This disfavors certain persons with unusual and controversial disabilities such as allergies and pain. Another issue is that the Swedish case law shows that courts do not always consider individual autonomy, which is a fundamental value in the treaties. Among other

\textsuperscript{154} See supra Part 2.


\textsuperscript{156} See supra Part 3.1.
things, courts request that a person with a disability use less costly alternatives, even though this may limit his or her equal opportunities to persons without disabilities in choosing items such as air travel and hotel stays. This restriction can be justified by the ethical platform that is universally recognized.157

Even though the treaties are based on postmodern disability polity, some tension exists among policymakers and disability activists on how the State Party should redistribute its available resources to finance costs for accessibility or compensation schemes. The problem is that the treaties did not establish a solution to this issue except a minimum standard to satisfy particular needs for those most vulnerable, such as persons with severe disabilities, women with disabilities and children with disabilities. This issue is of immediate interest in cases where certain persons with disabilities are compensated despite the fact that they do not incur any extra costs. This problem, identified as over-inclusiveness, is present because legislators and courts use cost effective strategies to simplify the administrative procedure, such as guaranteed benefits and standard assessments of disability and cost.158 To avoid this problem, critics of a compensation scheme argue that the state should redistribute its available resources to finance costs for accessibility instead of costs for a social security and insurance programs, which provide individual compensation. According to them, there is a risk that a compensation scheme will have a negative impact on public attitude. More exactly, it is identified as a means of charity and pity when a person with a disability is recognized to be reliant on others. This conflicts with the paradigm of generally accepted disability models, from medical to social or biopsychosocial, where persons with disabilities should be active citizens. Others who support the compensation scheme argue that it is necessary as long as society is not fully accessible.

Experience shows that the anti-discrimination legislation has not lowered the rate of unemployment and sick leave among persons with disabilities.159 The problem is that the legislation does not prevent employers from evading their duties. Employers can argue that persons with disabilities are unqualified for certain positions due to a lack of work experience or certain accommodation measure that may constitute a disproportionate burden or undue hardship on them.160 They further argue that the benefits are voluntary and up to each person to take advantage of this offer. In our opinion, this tension can be lessened to a certain degree by the fact that legislators mandate to transfer the payment amount to a public fund that covers costs for accessibility standard for persons with disabilities. This system would promote individual autonomy that is compatible with the treaties and postmodern disability policy.

This tension also reflects the strategy that the U.S. and Sweden have chosen. The U.S. has chosen to give priority to accessibility standards through its comprehensive anti-discrimination legislation – the Americans with Disabilities Act of 1990.161 As a result, the U.S. has gained a reputation as the world’s first and most accessible country for persons with disabilities. This has had an indirect effect on extra costs for persons with disabilities. The more accessible a society is, the less extra costs persons with disabilities will incur. By contrast, the Swedish Government is still reluctant to review

157 See supra Part 2.5.
158 See supra Part 2.1.1 and 2.2.
159 See supra Part 1.
161 See 42 U.S.C. § 12112 et seq.
the Swedish Discrimination Act of 2008 so that it will include inaccessibility as a form of discrimination. According to the Swedish Government, it would be very costly for public and private entities to adapt their information, services and programs to persons with disabilities. This has galvanized disability activists to manifest for a more accessible society every May until the anti-discrimination legislation includes such a form of discrimination. This discrepancy shows that if these countries absorbed each other’s legal approaches by developing similar compensation schemes and accessibility standards, then these countries would be ideal places for persons with disabilities to live. Although it is highly probable that the Swedish Government will propose that the Swedish Discrimination Act of 2008 include inaccessibility as grounds for discrimination, the question remains whether the U.S. will be ready to introduce a generous compensation scheme in the future. The problem is that the Swedish example shows that much tax money is spent to finance the administration and monitoring system of childcare and disability benefits. Much time must be spent to assess the causal link between a disability and a claimed cost, which is not an easy task for clerks and judges. Such an experience can discourage the U.S. Congress from amending its SSDI program to cover more extra costs. It can be noted that Congress is currently debating how to make it more difficult for persons with disabilities to get the SSDI and SSI with the objective of limiting federal tax money to these benefits. This debate stems from the fact that the number of persons with disabilities who receive benefits has been steadily increasing since the 1980s reform.

4 Recommendations For Advocates and Legislators

In conclusion, based upon our research and review of the issues, we provide the following recommendations to assist legislators, policymakers, and disability advocates in their efforts to improve the quality of life for persons with disabilities, by improving established compensation schemes to compensate all types of extra costs that persons with disabilities may incur, we invite you to consider the following:

- Utilize the medical model of disability to provide the best legal definition to determine who should be covered by a compensation scheme.

- Use the biopsychosocial model of disability to ensure that the medical model definition appropriately matches disabilities with levels of compensation.

- Clarify the concept of extra costs to determine what the compensation scheme covers for persons with disabilities.

- In the case that multiple forms of compensation are used, clarify how these multiple forms can be claimed, whether they be claimed together or must remain mutually exclusive.

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164 Morton, supra note 67, at 2013.

• Make a determination of the causal link between individual disabilities and extra costs through the recommendations of medical experts, giving also the possibility of a second opinion.

• Utilize a subjective method, which allows individuals to determine their own needs, and objective method of cost assessment, which compares groups of persons with disabilities at similar income levels and with similar disabilities to groups of abled individuals at the same income levels, to determine appropriate compensation.

• Determine the legal scope of public entities’ primary duty before determining the State’s secondary duty to compensate extra costs, allowing for the ability to make claims against the primary duty-bearer to receive compensation.

• Establish a budget plan which balances of public income (tax revenue, interest on loans, property returns) and public spending (infrastructure expenses) to ensure the feasibility of financing a compensation scheme.