Chapter 1

Introduction
This study reports on European disability policy and the position of people with disabilities in Europe. In this introductory chapter the background of the study will be presented, followed by the objectives, research questions and outline of this thesis.

1.1 Background

Disability issues in Europe are of growing importance. This is not only demonstrated by ongoing policy developments at the European level concerning disability and people with disabilities during the last 15 years, but also by the growing number of people with disabilities, for whom this policy is especially relevant. Surveys conducted in all EU Member States have shown that about 16% of the population aged 16-64 has a long standing health problem or disability and that 3.4% has a severe health problem (Eurostat 2005). The prevalence of these health problems increases significantly with age, as on average, 2.7% of subjects aged 25-34 reported a severe health problem, and this proportion increases to almost 14% for the 55-64 age group and is at 39% among subjects aged over 85 years of age. The proportion of those who reported themselves to be moderately disabled increased from 8% in the 25-34 age group to almost 29% in subjects over 85 years of age. With the ageing of the European population, disability issues will become a more important determinant of a country’s health policy. European data over the last 15 years, however, shows that with an increase in life expectancy there seems to be a slight decrease in the most severe disabilities, but simultaneously a stronger increase in the least severe handicaps (EC 2003). This increase in the least severe disabilities may have been determined by the substitution of non-disabled years with years of minor disabilities and a shift from severe to less severe problems. This trend suggests the effect of public health policies (Perenboom et al. 2004). For the next decade the number of people with disabilities is expected to increase in Europe.
At the same time an active health and social policy may have an effect on the position of persons with physical and mental disabilities and may also mitigate the expected increase in their numbers (Jacobzone, Cambois & Robine 2000). However, these trends in disability are not only an issue for national policies but have become a common European issue too. Because of developments in policy and legislation in areas outside the domain of health and social policy, such as the freedom of movement of persons/workers, goods, services and capital and developments in the field of human rights and anti-discrimination, a coordinated ‘European disability policy’ seems desirable.

1.2 Objectives

From the perspective described above it seems very relevant to take a closer look at disability policy with a broader European scope. Such a scope may refer to policy at two levels (Hvinden & Halvorsen 2003). On one hand, it refers to disability policy at the level of the European Union (EU) as it has developed over the last 15 years, mainly as part of social policy. On the other hand, it refers to the country level within member states of the European Union. Disability policies at the national level have a longer tradition and a broader scope than social policy, which includes the domains of education, health care, housing and transportation.

Regarding disability policy in Europe, we will first take a closer look at the disability policy at the EU level. What is the current state of European disability policy? What has been done so far? How has it developed? And is the EU capable of influencing the national policy agendas of its member states, and what instruments are used to implement European policy measures?

Secondly, the focus will be on disability policy at the national level. Obviously, because of societal and economic developments across member states, differences have emerged between member states concerning the organization of healthcare and social care services and their infrastructure (expenditures, financing, and insurance). These historical and cultural factors are known to be persistent and to affect the process of change and the policies targeted towards the integration of disability policy at the EU-level. Therefore, it seems relevant to study the similarities and differences between national disability policies across European countries and to explore whether, and to what degree, these national policies reflect policy developments at the European level.

Considering the viewpoint that health policy may “make a difference” (Jacobzone, Cambois & Robine 2000), a subsequent major enquiry is to try and find out whether this is the case or not. In other words: does disability policy improve the functioning of people with disabilities, and if so, how does it work? Do different policy types and measures result in different situations for people with similar disabilities?
The objective of this study is two-fold:

- to analyse the development of disability policy at the level of the European Union as well as to study cross-nationally the similarities and differences in disability policy in various European countries, including an analysis of the relation between policy at the EU and the national level;
- to compare the situation of people with disabilities in a number of European countries and to explore the relation between these situations and the policy circumstances in these countries.

1.3 The European/cross-national policy study

On the initiative of the European Union, the Council of Europe and other (international) organizations, several international comparative studies have already been carried out on aspects such as employment, reintegration, working capacity and social security (Thornton & Lunt 1997; ECOTEC Research and Consulting Ltd 2000; Bloch & Prins 2001; EIM Business and Policy Research 2001; Van Oorschot & Hvinden 2001; ILO 2002; Soriano 2002; OECD 2003; Prinz 2003; Cahu, Lequet-Slama & Velche 2004). Also there are studies in which the definition or assessment of disability in European countries is a central issue, although often in relation to the labour market (Mabbett 2002; CoE 2002a). Finally, studies have also been published which describe the policy and legislation in European countries (EC 1998; CoE 2002b), but not in the integrated and comparative way and with the broad scope of this study.

The research questions of this first part of the study are:

I.1. What is the present state of disability policy at the EU level? Which issues are important, what are the objectives and how does “Europe” try to achieve these goals?
I.2. What are the similarities and differences between national disability policies?
I.3. How do the EU policy and national policies relate to each other, and do initiatives at the EU level succeed in influencing national policy agendas?

Regarding disability policy at the European level, an analysis will be made of the contents of documents, resolutions and decisions of the European Council and the European Commission. To study the similarities and differences between national policies, a structured questionnaire was developed that covered aspects of general disability policy, education, work and employment, self-care and domestic life, mobility and transportation, and community, social and civic life.
The following characteristics, which are important in view of mainstreaming, inclusiveness, equal opportunities and participation (EC 2004), were analysed:

- the coherence or fragmentation in formulated policy and legislation, including anti-discrimination or equal opportunities legislation; general or specific legislation;
- the coherence or fragmentation in policy implementation; the level (central-intermediate-local) and number of organizations involved;
- the influence of (organizations of) people with disabilities on policy and legislation, implementation and service delivery, on the central and local level.

The countries that participated in the current study were: Belgium, Denmark, Finland, Germany, the Netherlands, Romania, Slovakia, Slovenia and the United Kingdom. With regard to the participating countries, we aimed for a more or less geographical representative distribution across Europe as follows: two or three northern European countries, two or three western European countries, two or three southern European countries and two or three Central European countries.

1.4 The exploration and comparison of the living situation

An obvious and important, although difficult, next step after analysis of a number of national policies was to establish whether the policies achieved the planned effects and whether different policies resulted in different effects. As a first step, the objective of the second part of the study was to investigate how people with disabilities fare under similar or different policy circumstances, and whether different policy types and measures result in or are related to different situations for people with disabilities.

A major issue in this respect is how to measure the outcomes of policy. Thus, the question is which outcome measure can be used to determine the effects of policy and policy measures on the living situation of people with disabilities?

A general objective of disability policy in Europe (CoE 2002b) is to improve the conditions and opportunities for people with disabilities to live a ‘full life’ and to enable them to attain their own personal goals as ‘full citizens’. An important condition for this objective is that people with disabilities have the same opportunities and possibilities to participate in society and can act in the same social roles as people without disabilities. Often the rather abstract policy objective of ‘full citizenship’ is then translated into more concrete and tangible goals concerning social participation. In the International Classification of Functioning, Disability and Health (ICF) participation is defined as ‘involvement in life situations’ (WHO 2001), such as being in paid work, being at school, doing one’s own shopping, running one’s own household, doing voluntary work, participating in cultural events or in active sports, etc. Seen in this light, social participation is objectively measurable and can be used as an outcome measure to determine the effects.
However, social participation can also be seen as an intermediate outcome measure. As such, it is not an end goal in itself but is a means of attaining full citizenship. Among other means or resources (Delhey 2004; Haller & Hadler 2006) it enhances opportunities and possibilities for people to lead a satisfactory and full life in the way they wish and enables them to attain their personal goals and objectives. This relation has also been investigated in the disability field (Post et al. 1998; Dijkers 1999; Levasseur, Desrosiers & Noreau 2004; Whiteneck et al. 2004; Van Campen, Iedema & Wellink 2006; Van Campen & Iedema 2007).

Thus, objective indicators concerning social participation are not the only indicators serving as outcome measures of disability policy. Subjective assessments of life circumstances such as ‘satisfaction with life’ or ‘subjective well-being’ are also needed to try to determine the effects of disability (i.e. social) policy (Diener & Suh 1997; Veenhoven 2002; Fahey, Nolan & Whelan 2003; Ferring et al. 2004). Furthermore, Veenhoven has argued that ‘happiness’ can be measured adequately across countries (Veenhoven 2000). Both social participation and subjective well-being can be used as outcome measures to determine the effects of disability policy.

In the ICF (WHO 2001), in the (reciprocal) pathway from (impairments in) body functions and structures to activity (limitations) to (restrictions in) participation, a clear role is assigned to two contextual factors: environmental factors and personal factors. Environmental factors are defined as the physical, social and attitudinal environment in which people live. They include, among others, health care and social policy, systems and services and – in our study – disability policy circumstances. Personal factors, which are not specified in the ICF, are characteristics of the individual, such as socio-demographic factors and self-rated health and mental and economic conditions. The role of these characteristics has been previously researched with regard to various chronic health or disability problems (Whiteneck, Tate & Charlifue 1999; Bent et al. 2001; Cardol et al. 2002; Jette et al. 2005; Van Campen, Iedema & Wellink 2006; Desrosiers et al. 2006; Van der Mei 2006; Carpenter et al. 2007).

The general question of the second part of this study is:

- do different policy circumstances (i.e. countries) result in or are they related to different degrees of social participation and subjective well-being of people with disabilities, in addition to individual socio-demographic characteristics and self-rated conditions?

To explore this question we will use a staged model (Figure 1.1, overleaf), as is also used in research on ‘successful ageing’ (Litwin 2005; Litwin 2006). In this study, social participation in the first stage is seen as an intermediate outcome or dependent variable, and in the next stage, along with the socio-demographic characteristics and the self-rated health and mental and economic conditions, as a possible determinant (i.e. independent variable) of the final outcome variable: subjective well-being.
An important question in this study is whether the different possible determinants (the independent variables, i.e. socio-demographic characteristics and self-rated conditions) are universal, that is:

- do they work the same way for people with and people without disabilities?
- do they work the same way in the individual participating countries (which represent the different or similar policy circumstances)?

As socio-demographic characteristics, we specifically considered those which are also frequently used in other studies: age, gender, living arrangement, level of education, and income (Litwin 2005; Desrosiers, Noreau, Rochette, Bourbonnais, Bravo & Bourget 2006; Van Campen & Iedema 2007).

As we are primarily interested in the pathway from disability to social participation in different countries (i.e. under different policy circumstances), controlling for socio-demographic factors, self-rated health and mental and economic conditions, and subsequently in the pathway from disability to subjective well-being, controlling for the same individual factors, including social participation, we will approach the research question in a stepwise fashion and by means of a series of specific and consecutive research questions:

- Step 1 (Figure 1.2)
As (the degree of) disability is the key independent variable in our study, in step 1 only the effect of this variable on social participation is described. The research questions in this step are:

  - II.1.1. are there differences in social participation of people with and people without disabilities between countries, and if so, how large are these differences?
  - II.1.2. are there differences in social participation between people with and people without disabilities within countries, and if so, how large are these differences?
• Step 2 (Figure 1.3)
In this step we try to explain social participation and the differences between people with and people without disabilities. If such differences can be found, the research questions are:

II.2.1. how are socio-demographic characteristics and self-rated health and mental and economic conditions associated with social participation of people with and people without disabilities, and to what degree do these factors contribute to social participation in addition to disability?

II.2.2. Concerning these factors, are there differences between countries in the association with and in the contribution to social participation?
• Step 3 (Figure 1.4)
As in step 1, only the effect of our key independent variable, (the degree of) disability, on the dependent variable, subjective well-being, is described.
The research questions are:
II.3.1. are there differences in subjective well-being of people with and people without disabilities between countries, and if so, how large are these differences?
II.3.2. are there differences in subjective well-being between people with and people without disabilities within countries, and if so, how large are these differences?

• Step 4 (Figure 1.5)
As in step 2, in this final step we try to explain, in this case subjective well-being.
The research questions are:

II.4.1. how are socio-demographic characteristics, self-rated health and mental and economic conditions and social participation associated with subjective well-being of people with and people without disabilities, and to what degree do these factors contribute to subjective well-being in addition to disability?

II.4.2. Concerning these factors, are there differences in the association with, and in the contribution to, subjective well-being between countries?

1.5 Outline of the thesis

After this introductory chapter, the methodology used in this study is described in chapter 2. First we will focus on the qualitatively oriented policy study and then on the quantitatively oriented comparison of social participation and subjective well-being of people with disabilities in the participating European countries. Chapter 3 will present the results of the first part of the study, i.e. the study on disability policy on the European level (research question I.1), on the similarities and differences between the national policies and policy measures (research question I.2) and on the relation between the European and national levels (research question I.3).

In chapters 4 to 8 the outcomes of the quantitative comparison (the second part of the study) will be given. Chapter 4 describes the differences in social participation between the countries (research question II.1.1), while chapter 5 describes the differences in social participation within the countries (research question II.1.2).

Chapter 6 presents the associations between the socio-demographic characteristics and social participation of people with and people without disabilities, and the degree to which these factors contribute to social participation (research question II.2.1 and II.2.2). Chapter 7 describes the differences in subjective well-being between and within the countries (research question II.3.1 and II.3.2), and chapter 8 presents the associations between the socio-demographic characteristics, the self-rated conditions and social participation and subjective well-being of people with and people without disabilities and the degree to which these factors contribute to subjective well-being (research question II.4.1 and II.4.2).

In the final chapter we will consider the outcomes of the previous chapters together. We will discuss the main findings and will explore the question of whether the differences in social participation and subjective well-being are related to differences in policy circumstances. We will then consider a number of methodological issues and close with recommendations for policy and research.
References


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