

A person in a wheelchair is shown from behind, looking towards a large map of Europe. The map is surrounded by twelve yellow stars, similar to the European Union flag. The scene is set against a blue and orange gradient background, suggesting a sunset or sunrise. In the foreground, there are silhouettes of several people standing in a line, some holding briefcases, suggesting a professional or public setting.

Living with Disability in the EU

How citizens' rights challenge
the European Social Model

Living with Disability in the EU: How citizens' rights challenge the European Social Model.

Doctoral Thesis

Author Tobias Nickl
Supervision Prof. Dr. Monika Eigmüller
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Europa-Universität Flensburg (EUF)
Institute for Social Sciences and Theology

Abstract

The EU treaties guarantee all EU citizens the right to freedom of movement. However, this right is not unconditional. To reside longer than three months in another Member State, EU citizens must have sufficient financial resources for themselves and their families (Art. 21 TFEU). The underlying presumption is that foreign EU nationals must not become a burden on the social system of the host Member State.

People with physical and/or mental impairments are often disabled from participating in the so-called first labour market and face a significantly higher poverty risk. Additionally, they are more likely to depend on personal assistance services and social welfare to cope with everyday life. This dependency may disable them from exercising their right as European citizens to move and reside freely within the European Union. The area of tension lies between the principle of non-discrimination and equal treatment of disabled people on the one hand, and the financial sustainability of national welfare systems on the other.

This thesis analyses whether disabled people's right to free movement contributes to reforming the European Social Model (ESM) from a charity-based understanding towards a rights-based approach. It becomes apparent that the increasing significance of the 'social model of disability' increases the tension in three key social policy areas: non-discrimination of disabled people, the coordination of social systems, and access to social services of general interest (SSGI). The findings have been discussed with experts from the European Commission, the European Parliament, the Council, key stakeholders, disability lobby groups at the EU level, regional authorities in the EMR, and local service providers who have experience with the cross-border mobility of severely disabled people.

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Introduction: Living with Disability in the EU

„We want to live more independently than we have until now. For that, we need other people. (...). Mentors should help us to do things independently. They need to be patient with disabled people. We want to work together, but we are not recipients of orders.”

(Declaration of the Association Lebenshilfe Germany, 1994)

When interacting with others, disabled people often experience assumptions and prejudices: Prejudices about what disabled people are (not) able to do, as well as assumptions about where their priorities lie (e.g. Kármán, 2021; Antonopoulos, 2023). Shaped by these prejudices, reality can often be surprising. For example, disabled athletes at the Paralympics are regularly assumed to have “*heroic powers*”¹. However, the real reason for the amazement of disability sports in recent years is the sports’ ability to emphasize the athletes’ strengths instead of their weaknesses. The same applies to our assumptions. Mentally impaired people are often assumed to be unable to see the bigger picture and thus lack the ability to form a reasonable opinion independently (Kármán, 2021). One of the manifold consequences is the exclusion of mentally disabled people from EU elections in seven EU member states (Vasques, 2024; Teglbjærg, 2021). Thus, prejudices can have a direct effect on EU citizens’ rights.

This thesis deals with the inclusion of disabled people in the European integration process and a fundamental right as EU citizens: Article 20 (1.a) of the Treaty of the Functioning of the European Union (TFEU) establishes the Citizenship of the European Union for all persons holding the nationality of one of its member states and defines their right to move and reside freely within the territory of the member states. To understand the issue’s problem, the implementation of this right into EU secondary law must be recalled. To many

¹ For example, in August 2024 Olympic Judo champion Teddy Riner called Paralympic athletes “Superheroes”

non-disabled EU citizens, the following is likely to be a matter of course. „*Union citizens should have the right of residence in the host Member State for a period not exceeding three months without being subject to any conditions or any formalities*” (Directive 2004/58/EC, Art. 6). Thus, contrary to popular belief, freedom of movement as foreseen in the EU Treaties is not implicit but limited to three months.

The problem for disabled people arises from the subsequent article. “*Persons exercising their right of residence should not, however, become an unreasonable burden on the social assistance system of the host Member State during an initial period of residence. Therefore, the right of residence for Union citizens and their family members for periods in excess of three months should be subject to conditions*” (Directive 2004/58/EC, Art. 10). Broadly summarized, the conditions to reside abroad for more than three months are that the person must have an income, be in education, or otherwise have sufficient financial means to cover all personal costs. This restriction needs to be seen in the light of the ‘European Social Model’ (ESM), which is essentially based on a consortium of independent national welfare systems. These systems differ in many aspects, such as financing, expectations, and scope, which has led to asymmetry in their performance (see e.g., Ferrera, 2005, Maschke 2008). This is also visible in government expenditures on social protection benefits for disabled people.

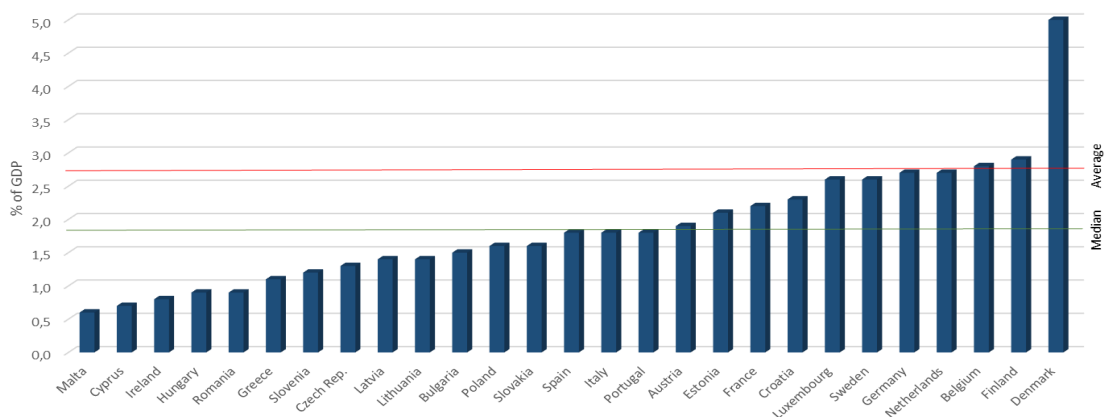


Figure 1: Government expenditure on social protection benefits for disabled people in 2020²

² Source: European Court of Auditors Special report 20/2023, p. 16

These differences in the government expenditures on disability result from differences in financing the national social systems. For this reason, the coordination of disability-related benefits in cross-border situations is a difficult task. As there is neither an EU-wide system of social security contributions nor a common system of providing social aid, the aforementioned restriction to freedom of movement aims to maintain the financial stability of the national social systems. However, this restriction also means that those who cannot get a foothold in the so-called primary labour market and depend on social assistance remain permanently excluded from the EU integration process (Ristuccia, 2022).

This situation disproportionately affects severely disabled people, who experience that the labour market often is not accessible for those with physical, mental, or intellectual impairments. The result is an increased risk of poverty and social exclusion (Maschke, 2008).

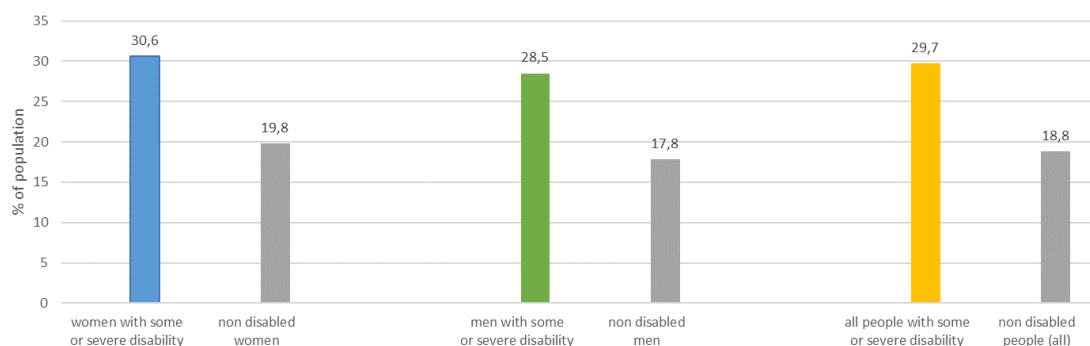


Figure 2: People at risk of poverty or social exclusion aged 16 years and older in 2021³

As Wansing (2014) points out, it is therefore crucial to understand the intersection of disability and migration, which is strongly affected by societal attributions. The EU member states have also recognized that restricting the right to freedom of movement could cause problems for certain population groups. For that sake, EU legislation on the free movement of persons already prioritizes EU citizenship, stating that “*it is necessary to codify and review the existing Community instruments dealing separately with (...) inactive persons in order to simplify and strengthen the right of free movement and residence of all*

³ Source: European Court of Auditors Special report 20/2023, p. 10

Union citizens" (Directive 2004/58/EC, Art. 3). With other words, the problem has been recognized two decades ago, yet it still exists today.

While there has been little progress in aligning the national social systems of the EU member states, social graces towards disabled people have changed substantially in the past twenty years since the Directive was passed (Zaks, 2023; Barnes, 2018). This raises the question of whether this 'European Social Model' of coordinating otherwise independent national social systems still matches a modern understanding of disability beyond assumptions and prejudices.

To substantiate this idea, it is worth looking at the declaration from the 'Lebenshilfe' association⁴ at the beginning. In the early 1990s, when the Maastricht Treaty formally established the EU, social services were generally viewed as a form of generous charity. While the motivation to provide services might have been with the best of intentions, it also reflected a disparity between disabled and non-disabled people. This could culminate in the expectation for disabled people to be content with what they were given. In a certain sense, this idea of generosity is also often reflected in the design of European social welfare systems (e.g. Withers, 2024). For example, while employers and employees commonly engage in wage negotiations, there are no similar negotiations between dependents of social benefits and the respective authority.

With declarations such as the one mentioned above, severely disabled people were demanding a different approach. Whether these documents have been the initial spark cannot be traced back, but it does show a clear shift from a 'welfare mentality' towards more equality. Essentially, disabled people refused to be 'pitied' because of their disability. Instead, they requested their rights to be recognized. This request had a significant impact on the daily lives of disabled people, particularly those living in institutional settings. Social workers have been trained differently, and step-by-step, daily interactions have changed (e.g.,

⁴ The Association 'Lebenshilfe' is a non-profit organization founded in 1958. It sees itself as an association to support disabled people and their families, of which many are members. Its local member organizations are active at around 5.700 locations throughout Germany.

Falkenstörfer, 2020; Bösl, 2010). A visible example of this change in mind is the rebranding of a well-known German funding program from '*Aktion Sorgenkind*' (Campaign Problem Child) to '*Aktion Mensch*' (Campaign Human Being)⁵ in the year 2000.

However, starting with grassroots organizations, the change request has not been limited to the interaction between disabled and non-disabled people. Little by little, the entire idea of disability being a deviation from a 'normal' health status has been questioned (e.g, Hughes; Paterson, 2006; Withers, 2024). The preliminary peak of this development was the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006. The EU and all member states have ratified the Convention, being the only multinational organization to commit itself to the rights of disabled people. One of these commitments includes that "*States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others (...)*" (UNCRPD, Article 18.1).

In the European Union, however, reality looks different. On the one hand, there are significant differences between the national social security systems, including government expenditures on disability. On the other hand, there is an increasing demand by disabled people to have their rights recognized as European citizens. The mismatch results from the EU disability and social policy lagging behind the development of how to view disability. This leads to disabled people experiencing discrimination concerning their ability to move and reside abroad and their exclusion from the EU integration process. For that sake, this thesis's research question is whether the right to free movement can drive the European social system from a charity-based understanding towards a rights-based approach.

While there is no question that disabled people have citizens' rights equal to others, the question of whether they can actively exercise these rights remains on another page. Being an active citizen involves exercising social rights and

⁵ The program funds projects to enhance the inclusion of disabled people with more than 500 million €/year.

duties, enjoying choice and autonomy, and participating in political decision-making that is important to one's life (Hvinden et al, 2017, p. 1). Thus, *"citizenship can provide a benchmark against which it is possible to assess the status of certain individuals or groups in relation to access to the agreed rights and (...) the levels and causes of inequality within a society"* (Dwyer, 2000, p. 3). In the context of being an active European citizen, this benchmark is the freedom to move and reside freely within the European Union.

The methods used to answer these questions are qualitative. In a first step, EU legislative and pre-legislative texts, public opinions by stakeholders, rulings by the European Court of Justice (ECJ), and other relevant documents are analysed. A special focus has been laid on the wording and intentions of these texts regarding understanding disability. This method is based on the narrative analysis developed by Bruner (2002).

The findings have been discussed with 12 experts from various levels of the policy cycle, including Members of the European Parliament, representatives to the Council's working group on social issues (including disability), and European disability lobby groups. Additionally, two experts from the European Commission have been consulted during webinars concerning specific legislation in their respective fields of expertise.⁶ These high-level assessments have been compared with the experiences made by regional and local experts, as well as a facility for severely disabled people with concrete experiences in hosting EU foreigners. This way, the impact of European social policy on people with disabilities is considered at all levels of the vertical hierarchy.

The interviewed experts for this thesis were selected based on a purpose sampling method. All experts have been chosen based on their experience, because they have either been directly involved in developing relevant EU policies, have gained practical experience with the cross-border situations of disabled people, or are themselves limited in their ability to move and reside abroad.

⁶ The European Disability Card and the Coordination of Social Security Systems.

Expert	Organisation	Function	Expertise	Consulted via
1	European Commission, Directorate-General for Employment, Social Affairs and Inclusion	Head of Unit D3 on Disability and Inclusion	Implementation of the European Disability Rights Agenda, in particular the EU Disability Card	Webinar on EU Disability Card at EDF, September 16 th , 2021
2	European Commission, Directorate-General for Employment, Social Affairs and Inclusion	National Expert of the Netherlands and Legal Officer on Social Security Coordination	Coordination of social security systems, in particular, Proposal to revise Regulation (EC) No 883/2004	Seminar on social security coordination at Maastricht University, September 25 th , 2024
3	European Parliament, Committee on Employment and Social Affairs	Member of European Parliament (MEP), Chair of EP Intergroup on Disability	Political developments in the EU Parliament regarding disability; mainstreaming of disability policies	Interview, January 20 th , 2023
4	European Parliament, Committee on Employment and Social Affairs	Political advisor to MEP Gabriele Bischoff, Rapporteur on reforming the coordination of social security systems	Political developments in the EU Parliament regarding social security, negotiations with the European Council	Interview, November 27 th , 2023
5	Council of the European Union, Working Party on Social Questions (SQWP)	Permanent Representation of Bulgaria to the EU, member of SQWP	Negotiations in the EU Council on social policy, including social security, the EU Disability Card, and anti-discrimination	Interview, December 12 th , 2023
6	European Economic and Social Committee (EESC), Permanent group on disability rights	Vice-Chair of Disabled People's Organization Denmark (DPOD), Member of the EESC	Implementation of the EU disability rights agenda; interface between stakeholders and the EU Commission	Interview, October 30 th , 2023
7	European Disability Forum (EDF),	Social Policy Coordinator	Strategies and limitations regarding	Interview,

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			lobbying for disability rights; development of the EU disability rights agenda	January 5th, 2023
8	Mental Health Europe (MHE)	Research and Policy Officer	Lobbying for people with psychological illnesses and service providers	Interview, October 16 th , 2020
9	Social Economy Europe	Policy Officer	Interests of providers of social services; overlaps and contrasts with service receivers	Interview, October 16 th , 2020
10	European Network on Independent Living (ENIL)	Policy coordinator	Strategies and limitations regarding lobbying for disability rights, in particular, the accessibility of services	Interview, April 16 th , 2024
11	Euregio Meuse-Rhine (EMR)	Speaker for the Aachen province at the EMR	Coordination on cross-border issues in the field of social and health policy	Interview, July 24 th , 2024
12	Agency for Independent Living in East Belgium (DSL)	Head of Department "Orientation"	Transnational placement of persons with disabilities in residential care facilities within the EU	Interview, September 11 th , 2024
13	The City of Aachen, Orientation centre for disabled people	Representative for disabled people	Support for disabled people when moving to another EU member state	Responds via E-Mail August 6 th , 2024
14	Facility for people with severe mental disability "Stiftung Dr. Dormagen", Cologne	Facility Manager & Occupancy Manager	Opportunities and difficulties in providing social services to a person from another EU Member State	Interview, November 14 th , 2024

Figure 3: Function and field of expertise of the interviewed experts

Expert 6 is a permanent member of the permanent study group on disability rights at the European Economic and Social Committee (EESC) and is directly affected herself: Even though she mainly lives and works in Brussels, she cannot move to Belgium without losing disability-related benefits from Denmark, including her wheelchair. Expert 3 is an elected politician chairing the Intergroup on Disability Rights within the European Parliament. She is currently the only MEP with a visible impairment and an active spokesperson for disability rights with a political agenda.

The interviews used a thematic analysis method to filter out recurring elements and contrast contradictions in the respective experiences. Eventually, this analysis will show that progress has been made in many relevant policy fields; however, apparent limitations also remain. After all, *“the stigmatization and separation of deviants have a stabilizing function for the social system (...)”* (Cloerkes, 2014). Nevertheless, in reverse, this means that combating stigmatization can have a destabilizing effect on the respective social system. Concerning the inclusion of disabled people in the European integration process, this thesis demonstrates that both are true.

The Three Levels of Active European Citizenship

“The notion of citizenship is frequently employed today at both national and European levels to deal with issues related to the social status of disabled people. (...). Thus, the concept of the enhancement of citizenship is used to focus on the social exclusion of disabled people from the mainstream of European social life” (Abberley, 2002, p. 121).

In order to answer the research question, whether the right to free movement can drive the European social system from a charity-based understanding towards a right-based approach, this thesis builds upon a previous research project that was conducted between 2013 and 2016 by a research group under the name *‘Making Persons with Disabilities Full Citizens - New Knowledge for an Inclusive and Sustainable European Social Model’* (DISCIT)⁷. The group consisted of researchers from nine European Countries⁸, as well as the European Disability Forum (EDF), and was coordinated by the Oslo and Akershus University College of Applied Sciences. Their previous research sets an excellent basis on which this thesis builds. The DISCIT researchers followed the question of whether national and European policies in Europe enhance Active citizenship within the nine participating countries. In that sense, *“effective citizenship (...) means being included in the systems of rights and welfare provisions that are mediated or managed by state agencies, and having one’s needs met through mainstream political intermediation”* (Harrison, 1995, p. 20; Abberley, 2002, p. 122). This thesis contributes to their work by asking how these policies function when disabled people are permanently moving between EU member states (and their disability systems) and thus actively exercising their *European* citizenship. Like Wansing (2014), it therefore connects the field

⁷ The DISCIT project has been funded through the EU’s Seventh Framework Programme for research, technical development and demonstration (2007-2013), the predecessor of the Horizon 2020 programme and Horizon Europe (2021-2026). It allocated a total budget of 623 million Euros to research in the field of socio-economic sciences and humanities, including research on political participation, citizenship and rights, as well as on social exclusion and discrimination. The DISCIT research project received 3.055.910 € in funding.

⁸ Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and the United Kingdom

of disability studies with the area of migration, however, with a focus on inter-EU mobility.

Because citizenship is used to reflect the social status of disabled people, the structure of the DISCIT project is being adopted for this thesis. It consists of three levels of influence: meta- or pre-political factors, factors related to the design of disability-related policy, and factors related to the implementation and enforcement of relevant policy.

Level of influence	Description
Meta- or pre-political factors	Issues related to the situation of persons with disabilities in general may prevent the topic of Active citizenship from entering the political agenda. This includes, for example, the way in which 'policy issues' are defined, as well as prejudices and stereotypes about persons with disabilities as being less able to exercise Active citizenship.
Factors related to institutional or policy design	Even if the topic of Active citizenship (or an issue related to it) enters the political agenda, the definition of specific goals may not receive sufficient attention. Consequently, Active citizenship becomes a marginal issue in the context of a larger topic, potentially resulting in an insufficient policy design.
Factors related to implementing the relevant policy	Insufficient practical coordination by the actors who are involved in the implementation of the disability-relevant policy. This may be unintentional because of the lack of clarity in legislation and governmental actors at a subordinate level that intentionally evade the requirements to protect their own operational autonomy.

Figure 4: Mechanisms potentially preventing public policy from enhancing Active citizenship⁹

⁹ Illustration based on Hvinden et. al, 2017, p. 7

Part I: Pre-political factors

The first set of pre-political factors describes those determining whether the needs and demands of persons with disabilities are part of the political agenda. In the context of this research project, this translates into questioning whether decision-makers at the EU level are aware of the barriers that disabled people face when moving abroad.

The DISCIT researchers have been inspired by two theories when defining which factors belong to this group. First is the normative social justice theory by the feminist and social philosopher Nancy Fraser (2013). Next to the redistribution of resources and the recognition of the individual social status, her theory on promoting social justice also includes the need for political representation (Fraser, 2013; Hvinden et. al, 2017). Moreover, she distinguishes between two different forms of how a socially disadvantaged group may be deprived of representation: The 'ordinary-political misrepresentation' when a particular rule makes it difficult for some people to participate or to elect representatives, and the 'misframing', meaning that the boundary-setting of the political process completely excludes an affected group (Fraser, 2013, Hvinden et. at, 2017). In the context of this thesis, the question is, therefore, whether there are pre-political factors that hinder disabled people (or a certain group) from representing their needs within the European policy-making processes.

Second, the DISCIT research group set up a general framework to illustrate how different groups are perceived by policymakers in terms of relevance (based on Schneider and Ingram, 2005). Certain groups potentially have a significant political impact and may thus be viewed as 'strong', while others are highly fragmented. Likewise, policymakers' views on certain groups may vary in positive or negative terms, partly depending on their political standpoint. Thus, *"the various combinations of such constructions or attributions are important for what political elites will expect of members of a category in terms of capacity, participation, and contribution to society, or conversely, in terms of demands, lack of participation and burden on society"* (Hvinden, 2017, p. 8). It is easy to imagine that at least some groups of disabled people (if not all) are facing

relatively low expectations by most policymakers. People with severe disabilities or mental illnesses are especially more likely to be seen as a burden to society that needs to be taken care of. For this reason, those groups are likely to be given less access to policymakers than others (Schneider and Ingram, 2005).

Both approaches to political representation may be criticized for being somewhat static, as neither considers the possibility of transformational social change. For example, the strong mobilization of disabled people on an international level has been essential to adopting the UNCRPD. Nevertheless, both approaches help to interpret pre-political factors that potentially harm the ability of persons with disabilities to exercise Active citizenship. Thus, they are the basis for Part I of the analysis on how freedom of movement for disabled people has been brought onto the EU policy agenda.

To determine whether the needs and demands of disabled persons regarding their rights as European citizens are part of the political agenda, Part I of the analysis focuses on two key aspects: the political framing of disabled people's European citizenship and their representation in political processes. Two guiding questions lead this research approach: How can disabled people engage in policy-making processes, and how are their interests being perceived by European decision-makers? In that sense, the perception of disabled people constitutes the independent variable that potentially affects the representation of disabled people on the EU level (dependent variable).

The analysis includes four analytical tools: First, the aspect of how disabled persons have been perceived until now in the EU is being analysed through a variety of EU documents, including an assessment of the European Disability Action plan (2004-2010) and the European Disability Strategy (2010-2020). The assessment focuses particularly on the wording and the goals formulated by the EU institutions. Having shown the status quo regarding the perception, the second analytical tool focuses on the institutional channels to include the interests of disabled people in the political agenda, including an analysis of the European Commission's public consultation before drafting the European disability strategy after 2020. The findings have been discussed for this thesis with several experts, including members of the European Parliament's

Intergroup on Disability and the European Economic and Social Committee's temporary study group on disability rights (Experts 1, 2, 3, 4, and 6).

Having analysed the institutional view on the one hand, the analysis continues by interviewing experts from the affected groups on the other hand. This includes, in particular, the umbrella organizations representing people with mental or psychological impediments and the umbrella organizations representing the sector of social service providers (Experts 7, 8, 9, and 10). The key questions to be addressed are: Which groups are (under-) represented? Do they have access to members of the EU institutions? Moreover, are they actively able to shape the political agenda, or are they passively reacting to policy proposals put forward by the European Commission?

Part II: Factors related to the design of disability-related policies

Even when the concerns of disabled people make it to the political agenda, it is no guarantee of receiving the necessary attention. Once decision-makers express willingness to take measures in a certain field, the goals of that policy are defined, and the corresponding legislative acts are drafted. This means, for example, that even when decision-makers recognize the issue of Active citizenship as relevant, they might have a different idea of what Active citizenship implies or fail to allocate the necessary budget. Instead, goals related to Active citizenship face a danger that the DISCIT researchers describe as the 'mainstreaming' of policies when they are being designed. This means that the interests of persons with disabilities are insufficiently concerted with other policy goals and thus, they become invisible (Hvinden et. al., 2017, p. 9). When that is the case, in practice, there could easily be a mismatch between the policy's provisions concerning the cooperation between different sectors and the design of necessary tools for the operating bodies to implement the policy properly (ibid.).

While this risk of mainstreaming affects legislation in all policy fields, it substantially impacts disability policies in general and Active citizenship in particular. This is mainly because of the misrepresentation of people with (severe) disabilities within the decision-making bodies (Waltz; Schippers, 2020). While the European Commission, for instance, has about 35.000 employees

who work on policy drafts, only a few have a diagnosed disability (according to experts 7 and 10). If the aim was to have a portrayal of the European society working for the EU Commission (which it is not), this number should be around 3.000 persons. The result of disabled people being absent in the institutions of public policy may eventually result in “*political invisibility*” (Hvinden et. al., 2017, p. 9).

Therefore, the main factors to analyse related to the policy design of Active citizenship are, first and foremost, how the interests of disabled people, despite this political invisibility, are translated into policy goals. Secondly, the analysis on policy design investigates whether the respective legislation is targeted directly at the issue of Active citizenship of disabled people or whether it is tangential to various policies that are, to a greater or lesser extent, coordinated.

However, as chapter 1.1 about assessing disability demonstrates, the term itself is far less explicit than it first seems. Likewise, the term ‘disability policy’ requires further explanation. On the one hand, when ‘disability policy’ is narrowed down to legislation that explicitly targets disabled people (and thus also includes the term), it neglects all policy fields that potentially have a strong impact on this group. This could range from social housing legislation to state aid and public procurement rules. On the other hand, the European Union ratified the UNCRPD in 2010. It bound itself to the general principle to “*take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes*”¹⁰. Thus, when ‘disability policy’ is used to imply all policies where the interests of persons with disabilities are to be considered, it would *de jure* include all policies of the European Union.

Therefore, a systematic narrowing of the term ‘disability policy’ is needed. However, the complexity of Active citizenship requires the analysis of multiple policy fields (see Halvorsen et. al, 2017, p. 12). Based on the DISCIT’s research groups’ findings regarding the significance for disabled people, ‘European disability policy’ is therefore analysed in the following three different categories:

¹⁰ Council Decision 2010/48/EC concerning the conclusion, by the European Community, of the United Nations Convention of the Rights of Person with Disabilities, Art. 4 c

<i>Sub-category of disability policy</i>	<i>Aim</i>
A cash transfer system	To provide income security for unemployed persons with disabilities and to compensate for higher expenses due to special needs (f.ex, barrier-free living space, special diet, transportation, or heating)
A service delivery system	To enhance the capabilities of persons with disabilities for active living, enjoy their independence, participate in significant society arenas (f.ex, health, care, or assistance services, education)
A social regulation system	To influence the functioning of markets and the behaviour of non-governmental actors to promote welfare policy objectives or human rights

Figure 5: Interacting sub-areas of disability policy¹¹

Regarding this thesis's research question of whether citizens' rights affect the European Social Model, the comparative analysis of the respective national disability policies (in the sense of the mentioned sub-areas) only plays a subordinate role. Instead, this research project adopts the sub-areas of disability policy to analyse how the EU's policies contribute to the coordination between the member states and thus, potentially affect the ability of persons with disabilities to move abroad.

In this context, the first two sub-areas are likely to be especially problematic as *“both the cash transfer and service delivery subsystems aim at retributing resources among differing population groups”* (Halvorsen et. al. 2017, p. 14). Since the EU has no redistributive competency in social affairs, these two subsystems touch the core factors that potentially hamper disabled people from exercising Active European Citizenship.

¹¹ Halvorsen, Waldschmidt, Hvinden and Bøhler, Figure 2.1 p.14

Therefore, Part II analyses the legislative acts in the three sub-areas in terms of how the issue is addressed (whether directly or integrated in a bigger context), whether/how the coordination between these sub-areas is foreseen, and how the concerns of persons with disabilities (or their representative groups) have been considered when drafting the legislative acts.

Part III: Factors related to the implementation of the relevant policy

Even after disabled people (or their representatives) have had access to decision-makers, and if their expressed concern has enjoyed a high priority during the policy process, there may still be a remaining factor that prevents Active citizenship, which is the implementation of that policy. These obstacles relate to effectively implementing adopted policies at the local level. Previous research has demonstrated gaps between the aim or the procedures of disability policies in theory and the execution of these policies on the local level (Neille, 2015; Hvinden, et. al., 2017)

This malfunctioning of legislation may become visible in two ways. First, problems may occur because the local authority does not comply with the higher-level legislation. Reasons for this may be unintentional, such as a lack of knowledge about local competency, insufficient coordination between the involved actors, or simply an understaffing of the local authority. There may, however, also be cases of intentional leveraging of policies concerning Active citizenship, especially when a revised policy implies the relocation of competencies against the interest of the local authorities.

A second reason why implementing policies regarding active citizenship may face difficulties is that the interaction with the affected disabled people proves the impracticality of established bureaucracy. For instance, if the policy aims to foster self-determination, a legislative tool could give disabled people direct access to their monetary entitlements.¹² This way, they could decide for themselves when and from whom they want to receive the assistance or care services they need. However, even if the local authorities are acting according to the legal requirements, the entitled disabled people may find it difficult to

¹² This has been a key aspect of the 'Bundesteilhabegesetz (BTHG)', a federal legislative act to implement the UN CRPD in Germany. As from January 2020 entitled persons may have up to three different budgets: For social housing, for care services and for assistance services.

make independent decisions when the entitlements are too fragmented, the application process is not suitable for the entitled group or if the local authority's staff is not used to advise people with specific disabilities (Halvorsen, 2018; Waltz/Schippers, 2020). Especially if the disability results from some form of psychological or mental disorder, when not carefully designed, a policy intended to foster Active citizenship may be ineffective or even result in a stronger dependency of the entitled person on their counsellors or supervisors.

Considering these dangers of insufficient implementation of EU policies, part III analyses the effectiveness of EU legislative acts in practice. While this is ultimately what it is all about, the research approach is also limited by the sheer number of local authorities, service providers, and people in Europe. Thus, an analysis of European disability policy in practice can only be exemplary. This raises the question about which example would be most suitable to identify best practices as well as shortcomings of European legislation.

For this reason, the analytical approach of Part III follows the logic of a best-case example, namely that of the well-established Euroregion¹³, where local authorities have a long-reaching tradition of cross-border cooperation. The idea is, that if implementing European disability policies to foster Active European Citizenship fails in these regions, it is also likely to fail when a person with a disability moves between two European regions that do not have established cooperation channels. At the same time, the analysis of how European disability policies are implemented in a Euroregion can potentially also identify best practices that could be applied elsewhere.

This thesis picks the Euregio Meuse-Rhine (EMR) around the border triangle of the Netherlands, Belgium and Germany to analyse the cooperation in the field of disability policy. The choice of EMR is based on several factors: First and

¹³ The term 'Euroregion' refers to a cross-border structure of multiple communities in two or more European countries that have intensified channels of cooperation, often to achieve an economic benefit. This cooperation also includes societal and cultural issues and is supported by the European Union. The first Euroregion was founded in 1958 and includes 130 communities along the Dutch-German border. Currently, there are 81 Euroregions within the European Union and its neighbouring countries.

foremost, it includes only communities within EU member states¹⁴, which enables the impact analysis of EU politics. Second, in the context of the provision of Social Services of General Interest (SSGI), the different languages of the provider and the receiver of SSGI are potentially a significant barrier, especially when the SSGI requires fluent language skills. Consequently, this potentially hindering factor needs to be part of the analysis¹⁵. The EMR includes French-, German-, and Dutch-/Flemish-speaking communities. While this conveniently matches the language skills of this thesis's author, this is not the main reason for picking the EMR, but rather that all three countries have very different disability systems.

The analysis is twofold to assess how European (disability) policy affects disabled people who move within the EMR: First, an empirical analysis of the regional disabilities statistics shows whether more disabled people have moved within the EMR since the EU ratified the UNCRPD in 2010. This analysis also includes assessing whether there have been differences regarding the type of disability, age, sex, or nationality.

This quantitative analysis is followed by a qualitative approach: Based on the above-mentioned sampling method, four expert interviews were conducted with the local authorities within the EMR. This includes local officials involved in implementing the policies of at least one of the above-mentioned sub-areas, as well as a service provider who has assisted disabled persons in moving across national borders in the EMR (Experts 11, 12, 13, and 14).

To sum up, the research question of whether citizens' rights of disabled people challenge the ESM is being assessed in three steps: The first step follows the question of who cares about this issue, whether there is a lobby for disabled people to address the problem, and what the means are to bring the topic to Brussels' and Strasbourg's political agenda. The second step asks how EU secondary law has developed in policy areas essential to disabled people,

¹⁴ This excludes, for example, the Euroregion Baltic (incl. Russian communities), the Østfold-Bohuslän/Dalsland Euroregion (incl. Norwegian communities), or the Insubria Euroregion (incl. Swiss communities).

¹⁵ This excludes f. ex. the Inn-Salzach Euroregion at the German-Austrian border or the Flemish/Dutch speaking Scheldemond Euroregion of Oost- and West-Vlaanderen, (Belgium) and Zeeland (the Netherlands).

namely anti-discrimination law, the coordination of social security legislation, and access to personal assistance. The overarching question of this analysis is whether the development in these policy fields conflicts with (or even directly affects) the 'European Social Model'. The study is complemented by asking how practitioners experience the mismatch between expectations and reality in EU law, and what the consequences are to disabled people. The analysis focuses on the Euroregion Maas-Rhine at the border triangle of Belgium, the Netherlands, and Germany. The reason for choosing this region is that there are established cooperation channels in numerous fields. Thus, problems and best practices regarding freedom of movement will likely be transferable to other border regions.

Research Layout	Part I: Meta- or pre-political factors	Part II: Factors related to institutional or policy design	Part III: Factors related to the implementation of the relevant policy
Research Topic	Representation and political lobby of disabled people in EU policymaking	Subcategories of disability-related policy <ul style="list-style-type: none"> • Self-determination / non-discrimination • Social security / Cash transfer • Autonomy / Personal assistance 	Euregio Meuse-Rhine (DE, NL, BE) as best-case examples for cross-border coordination in economic, cultural and social matters.
Guiding Question	Is cross-border mobility of disabled people a real problem and have disabled people the means to bring this topic on the political agenda?	Does the subsidiarity principle contradict citizen's rights at the expense of disabled people and are there attempts to challenge the ESM's status quo?	Does intensified coordination enable disabled people to exercise their rights as European Citizens?
Independent Variable	Representation of disabled people on EU level and their access to EU policymakers	EU policy fields: <ul style="list-style-type: none"> • Anti-discrimination and equal treatment • Coordination of social systems • Accessibility to social services (SSGI) 	Coordination between local actors (public authorities, service providers)
Dependent Variable	Problem-awareness by EU policymakers and disability-related policy agenda	<i>De jure</i> ability of persons with disability to move and reside abroad	<i>De facto</i> ability of persons with disabilities to move abroad
Analytical Tool	Analysis of Disability Lobby and its impact on EU Disability Strategies; Expert interviews with key stakeholders	Analysis of legislative acts and stakeholder's opinions; Expert interviews with EU officials, elected MEPs and EESC members, Council representatives	Quantitative analysis of affected people, qualitative analysis of disability systems within the EMR; Expert interviews with local officials and service providers.
Relevance to Research Question	Is the research topic regarded as relevant? Who is challenging the ESM's status quo regarding disability?	How is the issue of freedom of movement affected by disability-related EU policies and where is it challenged?	How do European policies affect Active European Citizenship of disabled people in practice?

Figure 6: Summary Methodological Research Layout

Framework: The European Social Model (ESM)

In a global comparison, Europe is often perceived as providing an above-average level of social protection. Some even go as far as calling Europe a “*lifestyle superpower*” (Freire, 2014, p. 43), referencing that roughly 7 % of the world’s population lives on this continent, yet European social policies add up to more than 50 % of the world’s social expenditure. Thus, it is not surprising that in academic discourses, the term ‘European Social Model’ or ESM has become a widely used catchword, not least for the title of this thesis. However, what is the European Social Model (ESM) besides the pure quantity of social expenditure? The term arose in the 1980s to constitute a European alternative to the American form of harsh capitalism. Very broadly, this alternative was based on the understanding that economic progress must be accompanied simultaneously by the development of social security (Pascual; Jepsen, 2005). Since then, the term has been used in many different contexts, to the effect that there is no clear definition.

Some prominent scholars in European Studies, such as Scharpf, have viewed the ESM as a common objective of the EU member states. This objective is the achievement of full employment, social protection for all EU citizens, as well as a decent level of equality (Scharpf, 2002). It is, inter alia, contracted in the Treaty of the European Union, which states that its member states “*shall combat social exclusion and discrimination, and shall promote social justice and protection (...)*” (Art 3.3. TEU). Thus, according to Scharpf, the ESM serves not only as a common goal but also as a motor for harmonizing social policies.

Others have argued that the ESM goes beyond being a common objective. Instead, it reflects an ideal situation (e.g., Esping-Andersen, 1999; Ferrera, 2001; Mau, 2009). This approach highlights specific national models, offering basic social protection to all citizens, very low levels of income inequality, and a high degree of collective bargaining. However, according to their view, the ESM is unlikely ever to be completed.

A third approach contextualizes the ESM in globalization. It assumes that the capacities of EU member states to achieve their social policy objectives

independently diminish reciprocally to global dependencies (e.g., Hemerijk, 2002; Vaughan-Whitehead, 2003; Sapir, 2006). Therefore, the ESM becomes a European cohesion instrument for a transnational social policy system in response to globalisation. Naturally, this view strongly focuses on the ESM's economic impact.

Finally, some scholars emphasise the political significance of the ESM in the context of democratic legitimacy (e.g., Jespsen; Pascual, 2005). They argue that the ESM is a political tool to create a European identity based on specific policy paradigms, which the EU institutions represent. To achieve this identity, the ESM is used for self-representation by EU policymakers and to justify their actions. Since this approach strongly depends on the expectations of eligible voters to which the EU institutions feel the need to adjust, the ESM becomes a constantly evolving project.

Theoretical perspective on the ESM	Feature
Identity	Assumption of a common European objective to achieve full employment, social protection, and equality for all
Goal / ideal situation	Highlighting specific national policies, social protection for all citizens, and high degrees of income equality
Instrument for cohesion	Focus on the need for a transnational and multi-level system of social policy in response to globalisation.
Political Legitimization	Social policies are used to self-represent EU institutions and legitimize their actions.

Figure 7: Theoretical perspectives on the European Social Model¹⁶

Thus, the term 'European Social Model' is anything but a clearly defined concept, yet whether citizens' rights of disabled people challenge the ESM depends on what is understood as the ESM. Redefining an ideal situation or

¹⁶ Based on an analysis of theoretical perspectives on the ESM by Leruth (2017)

even challenging a common European objective is not the same as challenging the use of social policies for self-representation. Challenging the ESM in one of the three theoretical perspectives would question the comprehensiveness of a European identity, an ideal situation, or a multi-level system of social policy to include disabled people better. In contrast, viewing the ESM as a tool to justify political action would require a more significant public interest in disability. Challenging the ESM as a tool of political legitimization would, therefore, require raising awareness of the fact that citizens' rights are being hurt to create a 'window of opportunity' that politicians can use. The analysis in the following chapters will look at both.

Regardless of the theoretical perspective from which the ESM is being regarded, it is fair to say that further integration or harmonization of social policy has been promoted throughout the history of the EU and its predecessor. However, it is widely agreed upon that the EU integration process has created an asymmetry between the efficiency of the common EU market on the one side and policies promoting social protection and equality on the other (e.g., Ferrera, 1998; Streeck, 1999; Scharpf, 2002; Schellinger, 2015).

This asymmetry originated from the Treaty of Rome that established the European Economic Community (EEC) in 1957. Its purpose included the establishment of a common market and the creation of a European Social Fund. As Hantrais (2007) points out, "*harmonization of social protection, as written into the EEC Treaty, implied that member states should work together and adapt their own social security systems to bring them into line with one another through a change in the substance of national law. It goes further than coordination, which involves linking separate legal systems at supranational level (...).*" (Hantrais, 2007, p. 28).

To state the obvious: While the subsequent EU Treaties deepened a common EU market for goods and services, there is neither a common European welfare system nor Europe-wide social security contributions to finance such a system. Instead, the national social models vary greatly in terms of their structure, their financing, and their effectiveness (see e.g. Ferrera, 1998; Barberis et.al., 2010).

Scharpf (2002) and Hantrais (2007) see a significant reason for this unequal development in the gradual enlargement of the EU, especially with the admission of Eastern European countries, where GDP and social protection remained much lower than those of Western European countries. Domestically, Germany had experienced a similar process with its unification and the inclusion of East Germany into its social systems. However, “[*the European harmonization of social protection*] falls short of unification (as applied to East Germany in 1990), which requires a fundamental reshaping of existing systems” (Hantrais, 2007, p. 28).

This shortcoming results in the above-mentioned asymmetry, in which the ESM, regardless of the theoretical approach, is based on the collection of 27 independent national welfare systems. The role of the EU is effectively limited to organising the so-called ‘open method of coordination’ as a policy tool regarding social issues, for example, in ascertaining common objectives or establishing EU-wide social indicators (e.g., de la Porte, 2002; Ferrera, 2005; Salais, 2006; Sapir, 2006).

Attempts have been made to bring together the very different social welfare systems throughout the development of the European Union. However, despite the EU member states agreed on including the promotion of social justice and protection in EU primary law in Article 3 TEU, social policies are commonly regarded to fall under the principle that “*the Union shall act only if and in so far as the objectives of the proposed action cannot be sufficiently achieved by the member states*” (Art. 5 (3) TEU). commonly known as the subsidiarity principle. Regarding this thesis’s focus on disability policies, the inevitable question is: What is sufficient?

This leads to the core of the European Social Model in the sense referred to within this thesis: The objectives of (national) welfare policies are largely perceived as the protection of the most vulnerable as well as taking care of those who otherwise could not live a life that most of the society considers to be reasonable (see e.g. Bickenbach et al., 1999). The thought of solicitude is deeply embedded in these protective objectives, which the member states may achieve themselves. Oddly enough, at the same time, “*the conventional welfare*

state is not interested in individual characteristics such as adequate moral behaviour, or biological working capacity. This approach is rooted in the use of categories [such as] unemployed people, ill people, disabled people, and so forth" (Bonvin, 2006, p. 221). The EU institutions are given an assisting and coordinating role to align these categories, yet regulatory competences to harmonize them are being denied. Key competencies in the social policy field remain at the national level (Mau, 2009). The question of whether the rights of disabled people challenge the European Social Model, therefore, becomes a question of whether their rights as European citizens contradict the protective, solicitous understanding of national welfare policies.

There is, of course, also legally binding EU legislation to regulate specific social issues. In the early stages of the discourse surrounding the ESM, these legislative attempts might have aimed to align socioeconomic gradients between member states. Today, however, EU social policies are strongly connected to the functioning of the European labour market. These policies are located outside the sphere of classical welfare policies and include areas such as employment rights, working conditions or access to health services. Most EU social policies eventually serve the higher purpose of ensuring either the free movement of workers or economic efficiency (e.g. Roberts; Springer, (2001); Salais (2006).

Other social services, such as access to childcare or assistance services for disabled people, are largely reserved for relatives of workers. Thus, they are likewise designed to ensure free movement, not of those affected but of their relatives. In other words, a severely disabled person is only eligible for assistance services abroad if the disability does not prevent him/her from working or if she/he is dependent on a non-disabled worker.

Having pointed out the mismatch between economic development regarding establishing a common EU market on the one hand and integrating social welfare policies on the other, the question arises whether the ESM is per se a non-reformable coexistence of independent welfare systems. According to an analysis by Leruth (2017), *"little progress has been made over the past five decades, despite the introduction of Social Action Programmes in the 1970s*

and the use of common social strategies in order to reduce disparities within the EU” (Leruth, 2017, p. 180). He argues, that not only has there not been progress towards a common European welfare system, but after the financial crisis of 2008 and the subsequent recession, “*a common interventionist social policy now appears controversial or even utopian*” (ibid.). Indeed, with the political development at recent European elections and nationalist parties gaining strength in the European Parliament, a fundamental social reform towards a European Social Union seems out of sight.

Nevertheless, European integration is not limited to fundamental reforms that replace existing systems. There are at least two alternatives to be considered. First, there is the possibility of developing a common social welfare approach among a restricted number of EU member states. While this could lead to significant disparities regarding the level of social security, it might also reduce the number of different systems from 27 to a handful. The second (and more likely) way is the gradual harmonisation of policies that affect single social policy issues.

In the past, European policymakers have been eager to demonstrate their affection for social policies. For example, in 2017, the EU member states agreed to establish the so-called ‘European pillar of social rights’ (EPSR)¹⁷. The term derives from the original three pillars of the European Union that were introduced with the founding Treaty of Maastricht in 1993.¹⁸ Thus, the wording of establishing a ‘European Pillar of Social Rights’ has not been shy on meaningfulness. Content-wise, the EPSR includes 20 principles that promise to reform three key areas. One of these areas includes, among others, chapters to improve the inclusion of disabled people and social protection (EPSR, Chapter 3, Principles 12 and 17). Thus, integration in selective social policy fields, including disability policies, seems possible.

However, while the EPSR has not been short on commitment, it lacked legally binding social innovations, and competence shifts from the national to the EU

¹⁷ COM(2017) 251

¹⁸ The three pillars were (1) European Community, (2) Common Foreign and Security Policies and (3) Police and Judicial Cooperation. The Pillars have eventually been disbanded with the Treaty of Lisbon in 2009.

level. The German foundation 'Stiftung Wissenschaft und Politik' (foundation science and politics) concluded in 2023 that *"if the EPSR is to be used in the long term to secure a specific European Social Model linking the welfare worlds, it must be underpinned with financial resources beyond its coordinating character"* (Hacker, 2023, p. 6).

Instead, the EPSR is accompanied by the introduction of a 'social scoreboard', as has been suggested by Schellinger (2015) two years earlier. This scoreboard comprises 15 social indicators, designed to monitor social disparities and progress in the member states. In many EU documents that affect social policies, the EPSR serves as a reference point.

To conclude, rather than illustrating the European Social Model's status quo, the European Pillar of Social Rights constitutes a summary of what the ESM's completion could look like in terms of social principles and objectives.

In that sense, the EPSR confirms what some scholars such as Esping-Andersen (1999), Ferrera (2001) or Pascual (2005) have argued decades before the EPSR came into effect. *"The vagueness and polysemous nature of the concept of the ESM results not only from the lack of discussion devoted to the concept but also from a political construction of a self-styled European social policy identity by the EU institutions. (...). It is far from being an exogenous factor but, on the contrary, very much a political project aimed at fostering a European identity."* (Pascual ,2005, p. 37). Challenging the European Social Model, as it is suggested in this thesis's title, therefore means questioning the status quo as well as the (partly uncompleted) principles of the EPSR, as well as questioning the political project to foster a European identity.

Research Layout	Part I: Meta- or pre-political factors	Part II: Factors related to institutional or policy design	Part III: Factors related to the implementation of the relevant policy
Research Topic	Representation and political lobby of disabled people in EU policymaking	Subcategories of disability-related policy <ul style="list-style-type: none"> • Self-determination / non-discrimination • Social security / Cash transfer • Autonomy / Personal assistance 	Euregio Meuse-Rhine (DE, NL, BE) as best-case examples for cross-border coordination in economic, cultural and social matters.
Guiding Question	Is cross-border mobility of disabled people a real problem and have disabled people the means to bring this topic on the political agenda?	Does the subsidiarity principle contradict citizen's rights at the expense of disabled people and are there attempts to challenge the ESM's status quo?	Does intensified coordination enable disabled people to exercise their rights as European Citizens?
Independent Variable	Representation of disabled people on EU level and their access to EU policymakers	EU policy fields: <ul style="list-style-type: none"> • Anti-discrimination and equal treatment • Coordination of social systems • Accessibility to social services (SSGI) 	Coordination between local actors (public authorities, service providers)
Dependent Variable	Problem-awareness by EU policymakers and disability-related policy agenda	<i>De jure</i> ability of persons with disability to move and reside abroad	<i>De facto</i> ability of persons with disabilities to move abroad
Analytical Tool	Analysis of Disability Lobby and its impact on EU Disability Strategies; Expert interviews with key stakeholders	Analysis of legislative acts and stakeholder's opinions; Expert interviews with EU officials, elected MEPs and EESC members, Council representatives	Quantitative analysis of affected people, qualitative analysis of disability systems within the EMR; Expert interviews with local officials and service providers.
Relevance to Research Question	Is the research topic regarded as relevant? Who is challenging the ESM's status quo regarding disability?	How is the issue of freedom of movement affected by disability-related EU policies and where is it challenged?	How do European policies affect Active European Citizenship of disabled people in practice?

Figure 8: Part I: Summary Methodological Research Layout

Part I: Bringing disability to the EU policy agenda

“People can be categorized into two groups. Those who constantly categorize people into two groups, and those who do not.”¹⁹

1.1 What is disability?

Most people have a broad idea in mind about who is to be considered as having a disability. However, when defining the term (and thereby segregating disabled people from those without), it usually becomes difficult to pack this idea into words. For some physical impairments, such as walking impediments or blindness, it might be comparatively easy to find a common public understanding. However, making a clear distinction in many areas is much more difficult. As many educators and parents know too well, there may be very different assessments on whether a child’s lack of knowledge derives from a learning or intellectual disability or poor teaching, or whether a child’s behavioural abnormality is rooted in mental impairment or an under-challenge.

However, to find answers to this thesis's research question, it is crucial to have a common understanding of disability. For the analysis of how disability potentially affects a person’s rights as a European citizen, a broad idea is simply insufficient. In more analytical terms, defining disability means defining the independent variable presumed to affect the ability to exercise Active European Citizenship, which constitutes the dependent variable.

Acknowledging the importance of having a common understanding of disability, the idea of defining a set of parameters that enable a systematic collection of quantitative data (and therefore a comparison of national disability systems) is charming from an analyst’s perspective. This, however, is problematic for multiple reasons: First and foremost, to add value to the discussion, any parameter requires a unit and a scale. A disability scale would consequently reach from ‘completely normal’ on one end to ‘completely abnormal’ on the

¹⁹ Retrieved from the business concept for a living facility for disabled people in Breisach am Rhein at the French-German border

other, making the 'degree of disability' measurable. Not only is this highly problematic on a practical level to define the normal (as the abovementioned examples illustrate), but the approach also contains the risk of being abused as a scale that defines a person's value to society. The danger of this way of thinking does not require further explanation.²⁰

The second problem in establishing a set of parameters to define disability is the simultaneous establishment of boundaries for the disability community (e.g. Bickenbach et al, 1999). Therefore, while it is not only problematic for those whose disability is at least partly covered by the parameters, it is likewise problematic for those who are *de facto* deprived of Active European Citizenship, but who would not fit into this scale. Parameters based on either health restrictions or impairments of intelligence, for example, could in many cases not be applied to those with an autism spectrum disorder (ASD). Despite being sportive or holding academic degrees, they often depend on assistance services.

A third concern in defining disabled people is the segregation from those who are considered 'healthy'. It is fair to acknowledge that groups are often defined to design targeted policies (sometimes depicted as 'identity politics'), enabling policymakers to tackle specific problems effectively. As for the unemployed, for instance, it is undoubtedly helpful to collect data on their income sources, marital situation, and so on to ensure their social security and reintegrate them into the labour market. However, there is a key difference in the broad field of disability, which is permanence. Every disabled person whose impairments cannot be eliminated is, therefore, unable to leave the group of 'disabled people', impeding honest inclusion.

Having outlined the difficulties surrounding defining disability, the obvious question is: How can disability be addressed?

The academic debate in disability studies around this topic is intense and far exceeds this thesis's research question (see e.g. Barnes; Barton, 2002).

²⁰ While most scholars in disability studies denounce this way of thinking, the criticism is not universal for all recipients of social services. As such, the German long-term care system is based on a system of five degrees of care (Pflegegrade). Disabled people may, detached from their need for assistance services, be categorized with a degree of care, entitling them to the respective care services.

Instead of engaging in this discussion, the following section lays out the predominant approaches as summarized by the Office for Democratic Institutions and Human Rights (ODIHR) in its guidelines to promote the political participation of persons with disabilities. Subsequently, the developments that led to the European Union's disability strategy today are being analysed regarding the underlying approach.

In general, approaches to defining disability can be classified into two main strands: the medical and the social perspective. The first is based on the notion that disability derives from an abnormal physical or mental condition. Usually, the benchmark for defining the norm is relative to age (otherwise, a toddler's inability to talk would be classified as a disability). This approach sees the origin of disability at the individual level, rather than the circumstances. The significance lies in the conclusion for an effective remedy: The medical approach assumes that disability should be treated solely by physicians and other health professionals to reduce or, in the optimal case, cure the physical or mental impediment caused by a disability. However, the concept of caring bears the danger of segregation and the need to keep the disabled person apart from regular participation (e.g. Oliver, 1983, Imrie, 1996; Bunbury, 2019).

In opposition to this approach stands the social perspective on disability, which sees the cause for disability not in physical or mental impediments but in an environment that is inaccessible for that person (e.g. Barnes; Barton, 2002). To illustrate this difference, let us again take the supposedly obvious example of a wheelchair-bound person. The medical perspective defines the person's inability to walk as his/her disability since being able to walk is considered the norm. On the contrary, the social perspective argues that if a wheelchair-bound person is, for example, unable to enter a building, the disability is not the person's inability to walk but the missing elevator.

These two perspectives are, to a certain degree, mutually exclusive. However, *“even the social model contains a medical aspect, which has been referred to as the medicalisation of the social model”* (Oliver, 2009). The lines are therefore not entirely clear, especially when two further approaches are added, which do not necessarily exclude each other. For one, there is the charity perspective,

which considers disabled people as people who suffer from their disability and thus deserve help. While it does not necessarily collide with the social perspective, it mainly appears in medical contexts. Finally, the human rights perspective is to be added, which stresses the equality of disabled people while pointing out that they are generally at greater risk of being deprived of their human rights. This risk is not confined to a physical or mental impairment, but may depend also on factors such as accessibility, economic structures that result in the exclusion of disabled people from social activities (e.g. Anastasiou and Kauffman, 2013). Thus, the human rights perspective calls on the responsibility of the entire society to take measures.

Medical perspective / Charity perspective	Social perspective / Human Rights perspective
<p>The medical perspective assumes that disability is an abnormal health issue that should be treated solely by health professionals. Therefore, disability can be treated, reduced, or even cured.</p> <p>This may lead to the charity perspective, based on the belief that disabled people are suffering and are mostly helpless. Therefore, they deserve help through charity.</p>	<p>According to the social perspective, disability results from an inaccessible environment or society. Therefore, society must ensure accessibility whenever possible and compensate for the remaining barriers through assistance services and tools.</p> <p>This may lead to the human rights perspective. It emphasizes that disabled people are equal to any other person; however, they are at greater risk of being deprived of their human rights, and states should make efforts to protect them.</p>

Figure 9: Perspectives on disability.²¹

²¹ Based on ODIHR/OSCE Guidelines to promote the political participation of persons with disabilities

There are, however, more perspectives on disability, one of which is the so-called 'cultural model' (e.g. Shildrick, 2012; Waldschmidt, 2017). This model focuses on the cultural narrative of disability, for instance, in movies, which shape our idea of what disability is. Thus, the distinction between 'normal' and 'disabled' is exposed as a social construction.

However, regarding the research question of whether citizens' rights of disabled people challenge the ESM, this distinction has, theoretically and legally, a significant impact. From a medical perspective, treating impediments that lead to a disability is subject to the EU's health regulations, which make a significant difference between medical conditions that occur while legally residing in another member state and pre-existing/congenital conditions before going abroad.²² From a charity perspective, EU law would be even clearer, since the directive on freedom of movement established that EU citizens may only reside in another member state for more than three months if they "*have sufficient resources for themselves and their family members not to become a burden on the social assistance system of the host Member State during their period of residence and have comprehensive sickness insurance cover in the host Member State*".(Directive 2004/38/EC Art. 7.1b) Therefore, charity and caring for disabled people remain in the hands of the member states.

From the social perspective, on the contrary, the answer may be much less clear. If, for example, a person cannot enter the labour market in another member state, the social perspective emphasizes the host member state's responsibility to ensure that person's full participation. This may be even less clear in cases outside the so-called first labour market, such as publicly subsidized workshops for disabled people. Likewise, while the freedom of movement directive is clear on its provisions regarding social assistance, it also demands its implementation without discrimination on grounds of disability (Directive 2004/38/EC Preamble §31) and an "*extensive examination of the personal circumstances*" (Directive 2004/38/EC, Art. 3.2) by the host state. It lacks, however, a definition of disability.

²² E.g. Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, Art. 3 (a)

As the ODIHR points out, “*persons with disabilities generally prefer perspectives based on the Social Model and the Human Rights model*” (ODIHR, 2019, p. 23) because of the focus on their inclusion in society and their general acceptance. Having this in mind, the subsequent section outlines two documents that are of key importance not only to disability studies but also to the EU’s approach: The WHO’s International Classification of Functioning, Disability and Health (ICF) from 2001 and the UNCRPD from 2008.

1.1.1 The WHO’s classification system of disability and the UNCRPD

The International Classification of Functioning, Disability and Health (ICF), first published by the World Health Organization in 2001, is a tool to classify a person’s health and health-related issues. It is widely regarded as a milestone in the field of disability studies and is the subject of intense debates around the question of defining disability.

The ICF is the successor of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) of 1980 and has been developed by the WHO to tackle the problem of incomparable data concerning the effects of medical impairments (see e.g. Bickenbach et. al, 1999). The most significant development, however, is that the tool considers the individual background, moving the approach from a purely medical perspective to a so-called “*bio-psycho-social Model*” (WHO, 2002, p. 25). It does so by subdividing the classification into four components:

- Body functions
- Body structures
- Daily activities
- Environmental factors

While each of these components contains a list of detailed codes, without context, they are insufficient to comprehensively describe a person’s state of health, functionality, and disability. Therefore, the codes are accompanied by so-called assessment criteria, which are crucial for considering individual

circumstances. They may describe, for example, the extent of damage to the body after an accident, the change over time, or the person's location. Especially considering the environmental factors component, these assessment criteria can severely affect whether a factor is a barrier, has no effect, or is even supportive. As for the previous example of an elevator that significantly supports a wheelchair-bound person, it might become a significant obstacle for a blind person if he/she loses orientation. Consequently, the ICF codes the same elevator differently for both persons according to their impairments.

Especially in the years after its publication, the ICF has been regarded by many as the medical perspective, for which it has faced heavy criticism (e.g. Shakespeare, 2013). However, this criticism appears to be primarily based on a misconception of the ICF as a 'disability ranking', which it is not.

First, the ICF must be seen in a much broader context of the WHO's mandate of promoting international health. One of its key areas of action is to collect and improve data and information. The ICF aims at exactly that. In that sense, while the ICF is most present in disability studies, its application is by no means limited to this field. On the contrary, it is designed to cover all health issues, including those that may cause a disability. An allergy, chronic headaches, or a minor visual impairment²³ are therefore classified in the same manner as a developmental disorder²⁴. Thus, in practice, the ICF may classify all human beings, blurring the point at which a person is considered 'disabled'.

Furthermore, unlike many EU documents, the ICF includes explanations of its wording. For example, *"the term 'functioning' refers to all body functions, activities and participation, while 'disability' is similarly an umbrella term for impairments, activity limitations and participation restrictions."* (WHO, 2002, p. 2). By summarizing medical impairments with social factors such as activity and participation under the term 'disability', the ICF might be regarded as an attempt to overcome the gap between the medical and the social perspective. For this reason, the ICF has developed into a key basis for numerous legal documents that concern disability by the time this thesis is written.

²³ ICF Chapter VII, Diseases of the eye and the appendages, (H54.3)

²⁴ ICF Chapter V, psychic and developmental disorders, (F80-F89).

The UNCRPD: A milestone for the rights of disabled people

Seven years after the WHO developed the ICF, the UN drafted a document of probably even greater significance, the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Its goal is to ensure and promote the human rights of disabled people and ensure that they enjoy complete legal equality. In the preamble, the UNCRPD states that disability is a regular part of living and of social life. Hence, it views disability from a social/human rights perspective.

The significance derives from the fact that the document has been signed by all EU member states, as well as by the European Union itself, making it the first human rights document that the EU has signed as its own legal body. Its implementation is monitored inter alia by the Academic Network of European Disability Experts (ANED) on behalf of the European Commission (e.g. Crowther, 2019). Furthermore, the UNCRPD was ratified by the Council of the European Union in 2009, which committed itself to its implementation. (Council of the EU, November 26th, 2009). On the grounds of this ratification, the UN Secretariat of the UNCRPD regularly reports on the implementation status. For that sake, the definition of disability in Article 1 UNCRPD is crucial for the EU's approach to disability policies:

“Persons with disabilities include 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.” (UNCRPD, Art. 1)

This definition includes two central elements. First, the definition is based on a person's physical, mental, intellectual, or sensory impairment and thus, the individual (medical) characteristics. As illustrated before, the problem with impairments is that it necessarily implies the existence of a 'normal' condition. The assumption of this status is reinforced by the wording *“equal to others.”* Bluntly said, one could ask 'impaired from what?' and 'equal to whom?' To illustrate this problem more concretely let us use the example of elderly people. In which cases are physical impairments of a senior citizen considered 'normal' for a certain age and at which point are they considered 'disabled'? While this

distinction may be irrelevant to the person's need for assistance, it may have tangible legal consequences regarding the person's entitlements.²⁵

Secondly, according to the UNCRPD, an impairment on its own does not necessarily constitute a disability, but it may disable a person from full and equal participation in society. Therefore, the UNCRPD's definition of disability also recognises the societal dimension of disability, making the individual's societal background the second element. This marks a significant change, which some scholars see as a paradigm shift from the medical to the social model (e.g. Degener, 2016). However, the problem with bringing the abstract and barely measurable aspect into the equation has been recognised by the UN Secretariat of the UNCRPD itself. Following a conference on the comparability of disability data, it recognized disability as being a "*complex and multidimensional issue*" (Conference of States Parties to the UNCRPD, 2015, p. 2) as well as the "*lack of a uniform definition and understanding of disability among countries*" (ibid.) that makes the comparison of existing data sets as well of underlying methodologies impossible.

The insufficiency of the UNCRPD's approach to disability as a definition for disability policies becomes most visible in the conference's acknowledgement that "*not all data that has been collected [by the states] has been reliable or relevant for the formulation of disability policies. In many countries, confusion still exists over what constitutes a 'disability', particularly in cases of minor or moderate disabilities.*" (Conference of States Parties to the CRPD, 2015, p. 4). Furthermore, it points out that significant difficulties remain concerning collecting meaningful data even in the presence of a common understanding. This is mainly the result of the stigmatisation of disabled people, especially those whose impairments are of a psychological or mental nature. As the Office for Democratic Institutions and Human Rights (OSCE) rightly analyses, "*the UNCRPD does not place restrictions on what qualifies as a disability, since it*

²⁵ E.g. The German social system distinguishes between 12 separate parts, the "Sozialgesetzbücher" (SGB), each establishing a different set of entitlements. The federal law that aims to implement the CRPD in Germany, the so-called „Bundesteilhabegesetz“ (BTHG) assigns assisting services for the integration of disabled people to the rehabilitation sector (SGB V), however only if the impairment occurred before the individual's 65th birthday. After that the person is covered by the long-term care section (SGB XI) and is therefore not entitled to rehabilitation services.

recognizes that disability is an ever-evolving concept" (OSCE, p. 20). For that sake, the conference has called to develop a common set of concepts and definitions.

Conclusively, although the UNCRPD is the basis for the EU's approach to disability policies, it does not offer a common understanding or even a tool. This does not disapprove of the UNCRPD's approach, since its goal is to promote human rights and fundamental freedoms and not to establish a legal basis or even a classification of disabilities. However, regarding this thesis's research question on the impact of disabled European citizens' rights on the EMR, the problem occurs when the EU, referring to the UNCRPD, sets no restriction on what qualifies as disability.

1.1.2 The significance of labour to define disability in Europe

To comprehend why the social perspective now challenges our understanding of social welfare, it is important to understand its evolution first. In that sense, it is worth acknowledging that the development of how disability is understood in Europe has been very different throughout the centuries. Traditionally, sociologists such as Durkheim (1964) or Topliss (1982) have distinguished fundamentally between pre-industrial and industrial societies. The reasoning behind this distinction is not a general inability to work (which disabled people did before industrialisation), but the increasing division and specialisation of production processes. Due to industrialisation, disabled people faced increasing difficulties meeting work performance standards expected by their production managers. Topliss concluded with "*an important truth about the social exclusion of disabled people today: that it is intimately related to our exclusion from the world of work*" (Topliss, 1982). It is thus fair to assume that in societies in other parts of the world, where industrialisation has a very different history, the question of disability is likely to have also been addressed differently.

In Europe, the equalisation of physical impairment and disability, previously described as the medical perspective, is considered by many disability scholars to have historical roots in the 18th and 19th centuries. (e.g. Oliver, 2012; Karim 2021). Some see the basis for this view on disability in the evolution of 'Ascetic

Protestantism', which values labour as a God-given task that is to be fulfilled throughout life (e.g. Barnes, 2018). The expectations of what is to be achieved until life ends were based on labour or, if not in the sense of production itself, a contribution that enabled production (e.g., giving birth and raising children). It resulted in a concentration and organisation of the entire way of living around work, eventually bringing the industrial revolution and capitalism to its breakthrough. This notion of labour as the ultimate purpose of life has been cultivated in many parts of Europe.

However, in societies where the value of a human being is connected to the labour output, impairment of any kind is inevitably problematic. While the previous chapter has illustrated the difficulty of defining what is 'normal', the focus on labour enables the comparison of work output. Unavoidably, this results in the oppression of those who have some form of physical or mental impairment exceeding the impairments of the average worker (e.g. Abberley, 2002). Considering that the (working) population had been growing at that time, in practice, this oppression related to the replacement of disabled workers by non-disabled workers.

In the first half of the 20th century, the high valuation of labour was complemented by ideas of a 'collective people' that were more important than the individual. This combination has culminated predominantly in fascist ideologies in Italy under Mussolini and in Nazi-Germany, but likewise under the Franco Regime in Spain and Eastern parts of Europe (Mart, 2017). The subordination of the individual behind a collective people translated into the expectation to contribute to this collective, with a defined allocation of roles, not only between women and men but also based on other physical characteristics. While this is problematic for impaired persons, connecting value and labour has been problematic for (non-disabled) European leaders, too. In Nazi-Germany, for example, many of the old and physically or mentally impaired had been serving in World War I. On the one hand, they were glorified as heroes who made sacrifices for the German people, on the other hand, they often had little left to offer that was considered of 'value' in terms of labour. Categorising them as disabled, including all the horrific consequences, would have led to a severe loss of acceptance of the Nazi regime among the Germans. On the contrary,

those who have not (yet) contributed to society due to a severe impairment were even deprived of their right to exist as a human being.

Considering the question of how the shift from the medical approach to the social approach of disability took place, two things are remarkable regarding the Nazi's ideology: First, the Nazi leadership put much effort into backing a medical approach to disability through the extensive misuse of pseudo-scientific medical research for the non-scientific purpose of categorising people based on physical appearances. However, even the Nazis took the individual circumstances into account, especially the (non-medical) circumstance of whether the individual had served in WW I or not. This is even more remarkable considering the horrific consequences of their radical inhuman ideology, which culminated in the euthanasia of the so-called 'T-4 program', killing about 200.000 mentally and/or physically disabled Germans, including small children and infants. Second, because of this lack of a clear definition, the ultimate decision of whose life was unworthy of living was subordinated to doctors and so-called 'consultants', resulting in broad arbitrariness.

It is worth pointing out that this equation of the individual value of a human being with their perceived added value to society in connection with labour has predominantly been present in Europe. In the United States, on the contrary, *"the Social Security Act (1935) provided for universal retirement, unemployment insurance, and welfare benefits for the poor and the disabled"* (Cowie, 2016 p.109). However, even in Nazi Germany, this equation faced public resistance with the ultimate success that the T-4-Program officially ended before the end of WW II²⁶.

After the horrors of euthanasia, the predominant aim was to keep this from ever happening again. The common understanding was that while it was agreed upon that the horrors of World War II should never be repeated, neither the focus on labour nor the idea that disabled people are a burden to society had been challenged. Instead, this was accepted as an unchangeable fact in the

²⁶ Although the Nazis' T-4-Program has been planned as a secret operation it has widely been known to the public. On August 3rd, 1941 Bishop Clemens August Graf von Galen of Muenster publicly condemned the killings – with effect. As more clerical figures followed his example, the public criticism of the program rose until it was ended within the same month. Until the official ending about 70.000 disabled people had been killed. However, the killing continued in secret.

same manner that disability as such has been equated with suffering. Those affected were considered pitiful because their lives were viewed as barely worth living. The result of this pity has been the idea that the suffering of disabled people needed to be solicitously alleviated, essentially treating them as permanently ill.

In practice, this solicitousness had to be organised in some form of welfare. As for the disabled, the solution was found in public institutions that could be described as some form of long-term hospital. That way, the basic human needs of disabled people could be met, while at the same time pooling the necessary expenses and thus, keeping the burden on society to a minimum that was considered acceptable. These institutions were often outside the towns, dislocated from society, e.g. in former army barracks or similar buildings. The choices of these locations were no coincidence. While it was accepted that disabled people had the right to live and that euthanasia should never be repeated, this by no means included the perception of their lives being worth living. Thus, a majority of non-disabled people did not want to be confronted with the 'suffering' of the disabled in their everyday lives or even the idea that they or their loved ones could become disabled themselves.

It took until the 1970s for this view on disability to be challenged. With the growing cultural influence of the United States on continental Europe in general, so did the American disability movement (Waldschmidt, 2019). It aimed to improve the living conditions for disabled people by fighting stigma. By the example of American disability organisations, disabled people and their relatives started to form organisations in Europe. With increasing activity, their main achievement became internalised by the public: that a disabled life can still be a life worth living.

It is perhaps this recognition that has led to the most significant change regarding the perception of disability: The more it is acknowledged that a disabled life can be worth living, the more it becomes clear that the living quality for disabled people is defined (and often harmed) by external circumstances. The most prominent scholar in disability studies who contributed to this viewpoint is the social scientist Michael Oliver (1990), who invented the term

'social model of disability' in the 1980s and 1990s. He focused on the idea that the initial individual model, which included the medical understanding of disability, fundamentally opposes the social perspective (Oliver, 1990). Once established, the social model gradually developed, especially by scholars in the United States and Britain (e.g. Barnes, 2018).

However, the process of closing the gap between theory and implementation in legislation repeatedly proved to be slow. For example, while it has not been exercised for decades, in Germany, it took until the year 2007 for the forced sterilisation of disabled people to be illegal. Today, it is still legal in 14 EU countries²⁷, and in three EU countries, it is even a common requirement to be admitted to residential institutions²⁸.

The acknowledgement of the relation between having the possibility to live a worthy life and the social understanding of disability has been accompanied by another influential factor, also from the United States: The growing liberal understanding that everybody decides for him-/herself what makes a life worth living. At that point, the solicitude approach to disability has been challenged. Instead of providing what is understood by the public to be in disabled people's interest, the focus shifted towards self-determination. As many social workers will validate, this transition has been anything but smooth. Especially, the relationship between the social workers who provided assistance services and those receiving these services shifted drastically from 'dependents' to 'clients'.²⁹

To assess this development further, it would be informative to compare the outlined development in Europe with the developments in other societies worldwide where the individual has traditionally been granted less power. However, this would exceed the scope of this thesis and therefore can only be recommended for further research.

²⁷ According to the European Disability Forum those countries are Austria, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, Hungary, Latvia, Lithuania, Malta, Portugal Slovakia.

²⁸ Belgium, France and Hungary. An overview over national legislation on this matter can be withdrawn from

<https://www.edf-feph.org/forcedsterilisationmemberstates/>

²⁹ How difficult this transition had been from the point of view of service providers has been reported inter alia by board members of several German social organizations such as the Franziskanerbrüder vom Heiligen Kreuz e.V. in Linz or the protestant Stiftung Liebenau

To sum up the historical development of how disability is viewed in Europe, it is not so much a question of a stronger emphasis on society vs. the individual, but rather a shift from asking 'How can the individual contribute to society' towards the question 'how can society contribute to the individual's self-determination?'. The consequence of this shift is a significant empowerment of the individual, which constitutes the root of the social perspective that now challenges the European social systems. At that point, we come back to the research topic of disabled people's abilities to move abroad within Europe, specifically their ability to choose to move abroad. The more disabled people are given the right to self-determination, the more the limits of this right are tested.

However, the fundamental challenge of the ESM addressed in this thesis results not solely from this shift but from the resumption of the focus on labour. This is visible in the European Commission's focus on combating poverty by bringing unemployed people into paid labour and preserving the right to movement to *workers* and those who are not considered harmful to the host state (TFEU Art. 44.1).

The impact the growing significance of the social model is going to have on the European labour market, as well as on welfare provisions, cannot be predicted. However, for the upcoming analysis, two thoughts need to be considered: The first thought is that the focus on labour output is already being challenged and has indeed changed, namely by the success of feminist movements. In the past, the labour market has been organised mainly by non-disabled men for non-disabled men, which has set standards regarding working days (5 days/week), working hours (8 hours/day), and output. This, however, left those who could not meet these standards at a poverty risk, affecting people with impairments and mothers or women who traditionally took on other forms of responsibilities alike. Despite the (still ongoing) difficulties women face in the labour market, their example proves that reorganizing labour into a less output-driven and more inclusive workforce is possible.

The second thought is that the increasing tendency to organise life around labour due to industrialisation was accompanied by a growing workforce in general, which enabled employers to replace disabled workers whenever their

output did not match the expectations. In most EU member states, today's labour market shows the opposite: The general demographic change results in a significant workforce decline in almost all professions. Whether this situation will eventually result in higher appreciation of disabled people's work is still to be proved. However, the discussion on using labour output as a scale to define and measure disability has already begun. Most prominently, it has been formulated in the provisions of the UNCRPD, which recognised the "*right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities*" (UNCRPD; Art. 27).³⁰ In line with that provision, the expert 3 (MEP Katrin Langensiepen, who is chairing the EP intergroup on disability), publicly demanded the gradual abolition of sheltered workshops for disabled people, because of their failure to include disabled people in the so-called first sector.³¹

1.1.3 How the EU institutions define disability

The European Union commits to prohibiting discrimination on the grounds of disability in its Treaties (e.g. TFEU Art 10 & 11), as well as in the Charter of Fundamental Rights (Art. 21). Furthermore, the Charter "*recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community*" (Art. 26). Similar provisions have a standardised text module to be added in the respective preamble of many legislative acts of the EU.

However, without having a common understanding of the group in question, there is a danger that these provisions will become hollow. For this reason, it is important to look at the wording of how the EU, particularly the European Commission, addresses the topic of disability. At the Commission's website on persons with disabilities, the opening sentence reads "*by 2020, one-fifth of the EU population is expected to have some form of disability*". While a definition is

³⁰ In Germany, the discussion on the organization of sheltered workshops is brought into the context of paying minimum wage or the height of pension entitlements.

³¹ She publicly demanded the abolition of sheltered workshops in interviews with the Deutsche Welle (DW) on March 21st, 2021, and with tagesschau.de on February 19th, 2022. In the interview for this thesis, she repeated this demand and referred to the positive feedback she received after her TV appearances.

missing, the wording implies that the Commission views disability as a person's characteristic rather than a circumstance.

One must search intensely to find the Commission's definition of disability. The clearest can be found in a staff working document accompanying the EDS 2010-2020. At this, the commission acknowledges that "*there is no EU-wide definition of disability*" (SEC (2010) 1323 final, p.4) before referring to the approach outlined before within the UNCRPD. Most striking, however, is the following statement:

"The definition of disability depends on its intended use: non-discrimination laws may be based on different criteria from those used to determine eligibility for state benefits." (ibid.)

Considering the topic's complexity, this vague definition is understandable. However, it is likewise problematic regarding the research question on the prerequisites for disabled people to be active European citizens. The same document certifies that the poverty risk among disabled people (and thus their dependency on state benefits) is 70 % higher than average (ibid, p. 6). Not only does this question the applicability of the non-discrimination clauses, but it also proposes the question of which data the European Commission uses when drafting European policies, since this indicates the respective target group.

The primary information source for the European Commission is the Academic Network of European Disability Experts (ANED), which receives funding from the EU³². The group runs the so-called Disability Online Tool of the Commission (DOTCOM), a database on the member states' national disability laws and policies, which can easily be filtered for separate themes such as employment or accessibility.³³ Additionally, in 2007, the European Commission financed a statistical analysis of men and women with disabilities in the EU.³⁴ Under the headline "*Men and Women with disabilities in the EU*" the study offers a

³² ANED is financed by the Rights, Equality and Citizenship Programme (REC) of the European Union.

³³ Accessible at <https://www.disability-europe.net/dotcom>

³⁴ DG Employment, Social Affairs and Equal Opportunities. Carried out by Applica & CESEP & Alphametrics. Accessible at <http://www.cesep.eu/publications.htm>

quantitative analysis of “*people in the EU with long-standing health problems or disability (LSHPD) [in] a series of issues concerning the extent of their ability to participate in employment and to access education as well as their income wage levels.*” (Applica & CESEP & Alhametrics, 2007, p. 8). In doing so, it promises nothing less than an “*analysis of data in relation (...) to the prevalence of disability among men and women*” (ibid.).

The data sources used for this study are mainly an ad hoc module on disabled people and long-term health problems from the 2002 EU Labour Force Survey (LFS), which is set against the 2004 EU Statistics on Incomes and Living Conditions. Eventually, conclusions are drawn regarding “*types of disability that restrict the ability to work*” (ibid.), as well as access to education, participation in the labour market, household circumstances, etc.

Using this approach, the study sees LSHPD as the independent variable, thus a fixed condition, potentially impacting dependent variables such as employment or poverty. This approach demonstrates that when it comes to the ‘hard facts’, despite the Commission’s acknowledgement that there is no Europe-wide definition of disability, the medical perspective remains predominant. The ECJ has confirmed this view in the cases ECJ Chacón Navas vs. Eurest Colectividades SAE and joined cases Ring/Werge vs. HK Danmark. Concerning different treatment of disabled people, the ECJ ruled that “*the concept [of disability] must be understood as referring to a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life*” (ECJ Judgement Case C-335/11 and C-337/11). However, in its judgment, the ECJ ruled according to Directive 2000/78, while at the same time acknowledging that the EU has ratified the UNCRPD, including the definition of disability as an “*evolving concept*”. Therefore, the ECJ’s ruling visualises the increasing discrepancy between existing EU law and the growing significance of the social understanding of disability

The origin of the discrepancy between how disability is understood and how disabled people are included in the European integration process traces back to the European industrialisation in the 18th and 19th centuries, which placed

labour at the focus of everyday life. The increasing separation and specialisation of production has produced a seeming comparability of output, which often results in the oppression of those who do not meet these new standards.

After the horrible euthanasia of the Second World War, when disabled people were deprived of their very right to exist, there has been a gradual development from a perception of 'pity' towards the thought that society as a whole is responsible for enabling disabled people to live a self-determined life. In the 1990s this development resulted in the social model of disability. However, the predominant focus on labour has remained, not least visible in the legal provision that reserves the right to move freely within the EU to European *workers*.

Within the EU, there is no clear definition of disability. The discussions around this fundamentally surround the sociological question of whether a disability results from an individual medical, mental or psychological impediment that is considered 'abnormal' (medical perspective) or from the society that fails to match the individual's needs (social perspective). The WHO has developed a tool that regards disability as the result of personal impairments in the context of the individual's social background (ICF tool). The UN Convention on the Rights of Persons with Disabilities, which the EU has ratified, builds upon the ICF by defining disability as a developing concept with no clear boundaries. While this idea has been the basis for EU disability policies, the ECJ has underlined the medical aspects of disability in two cases. The European Commission has also argued that "*the definition of disability depends on its intended use*". However, there is a significant problem evolving from this approach: Preventing discrimination on grounds of disability (to which the EU is committed) while making the definition of disability dependent on its context is contradictory and, to a certain extent, mutually exclusive.

1.2 How can disabled people influence EU policymaking?

The following paragraph assesses how the growing tendency towards individual self-determination has the potential to impact European social policy significantly.

Micro-level: How individuals influence European disability policy

While a purely judicial analysis would probably offer the most promising outcome regarding a direct effect on the individual case, however, it would most likely exclude the option of changing jurisdiction. As Expert 3 (MEP Katrin Langensiepen) points out, despite all political and legal barriers, past changes in legislation have shown that *“the path leads towards a European social union”*(Expert 3, 2023)³⁵. Discussions in Brussels often focus on how a future European Social Union should be designed, rather than discussing its necessity. For instance, in February 2023, the European Economic and Social Committee (EESC) organised a public hearing to discuss *“how to best develop a specific mechanism for detecting and monitoring social imbalances in the EU”*³⁶. Therefore, a judicial analysis of the status quo could not answer the above-mentioned research question. Likewise, a comparative analysis of the existing social security systems to find similarities or, at the very least, to find ground for economically and politically acceptable assimilations of the social systems, is not suitable in the context of this thesis. At its core, such a comparison would not only have to find similarities in how member states ensure social security and provide social services to disabled people, but it would also have to address the essential question of how the respective social security system is expected to perform. In other words, while all EU member states have some provisions on how to include disabled people in their society, the understanding of inclusion itself differs greatly.³⁷

Furthermore, to assess whether the increasing right to self-determination of disabled individuals may foster a European harmonisation process of social policies, a comparative analysis of the member states would need to assess

³⁵ She referred to the introduction of minimum wage as the most recent example.

³⁶ *‘Towards a European Social Union: the ‘Social Imbalances Procedure’*, February 3rd, 2023, Brussels

³⁷ See Chapter **Fehler! Verweisquelle konnte nicht gefunden werden**. Part III demonstrates this problem within the Euroregion Meuse-Rhine

these expectations over a time period. That is because more important than the Status Quo is the question of whether these expectations are developing towards similar directions in different member states. The complexity and extent of such a comparative analysis would far exceed this thesis's scope.

Instead, this chapter addresses the potential impact which individual behaviour may have on an organizational system in general, as well as on changing the European approach to disability in particular. From that, conclusions are drawn as to whether the MEP's assessment regarding the development of the European social model towards a European social union is valid. The assessment regarding actual political considerations that have been achieved in the key areas of coordination of social systems, the provision of SSGI and anti-discrimination provisions, and the potential power that individuals may have in any of these areas, is subsequently addressed in Analysis II.³⁸

The following strain of thought is built upon three considerations: First, when assessing individuals' impact on a changing system, it is important to have a common understanding of what constitutes 'individual action' vis-à-vis reactive behaviour. The assessment is built based on Giddens' (1986) structuration theory, which assumes an interconnected relationship between an individual's actions and the social rules and norms of that person's environment.

Second, it is followed by considerations of the potential impact that individual action may have on systems in a society. These considerations are based on Luhmann's (1992) thoughts on translating the less prominent chaos theory into sociological contexts. Finally, the assessment of how individuals may influence the European social system is complemented by evaluating the significance of individual cases at the ECJ regarding European disability rights, substantiated by previous research by Eigmüller (2017, 2021).

1.2.1. The basis for self-determination: Personal decisions

The individual decisions of those in a powerful position are more likely to have a significant impact. In the European Union, it does make a difference whether a decision is made by a Member of Parliament or a judge of the European Court

³⁸See Analysis Part II

of Justice. Likewise, individuals who find themselves outside the official functions, but also in a representative position, may experience a greater amount of influence. That is because she/he might represent an entire movement, an industrial sector, or because that person speaks on behalf of all disabled Europeans³⁹ (expert 7).

However, as shown in the upcoming section, individuals who are neither fulfilling an official position nor have a representative function may also have a strong influence. To comprehend how this might occur, it is essential first to comprehend a central aspect of sociology: the individual action itself. For that sake, one assumption is that individual actions are not coincidental but based on decisions. The intent for that decision may have very different forms. It could result from a rational weighting of benefits and risk, out of habit or an emotional feeling, be based on individual values or be regretted afterwards. However, underneath lies an individual decision. It is worth pointing out that just because it is assumed that the action is intended, that does not signify that the consequence of that action is intended, too.

From a sociological point of view, it is not only the conditions and the reciprocity of decisive actions but also the intention behind them. However, the question of what constitutes an intent for action is the subject of further discussion among sociologists. Some argue that action needs a purpose and results from an active decision between at least two options, which has been made *before* the action takes place (e.g. Olson, 1965; Coleman, 1990). Others see individual action as being influenced by collective experiences, which result in rules and thus, influence individual action (e.g. Giddens, 1986; Bourdieu, 1991). According to the latter, action is a behavioural flow, which can only be separated into separate pieces afterwards.⁴⁰ Instead of active decisions being based on individual values or pre-designed goals, this flow of action is influenced by collective values and their implementation in rules. Thus, according to the strain of thought, goals develop not before but *during* the action. Intentionality is thus not a prerequisite for action, but the ability to self-

³⁹ The EDF claims to represent more than 100 million disabled people within the EU. The EDF Social Policy Coordinator Haydn Hammersley represents their interests towards elected officials and policymakers.

⁴⁰ Anthony Giddens calls this a “durée”

reflect during the entire action process. Self-reflection contributes to consciousness, while the flow of action itself can be revised.

Typical of this structuring theory by Anthony Giddens is a systematically elaborated interaction between the individual and the strong determinative power of social, and thus superordinate, structures. In other words: „*Action generates structure, and structure enables action.*” (Bonß, 2013, p. 204).

Let us link these thoughts to the research question and the topic of disability policies: If individual action is embedded in a flow, it remains dependent on circumstances. However, the individual itself can, based on that theory, influence these circumstances. Regarding disabled people's ability to live and reside freely within the EU, this translates into the theoretical ability of individuals to influence the existing norms and regulations regarding disability, while at the same time being dependent on them.

Assuming that intentional results from collective values, Giddens offers another interesting thought: If actions result from collective values, they also contribute to their strengthening. On the contrary, unintended action flows challenge the collective values (and their implementation in legislation). Because unintended events and reactive behaviour to these events are inevitable, Giddens assumes that order and systems are constantly being revised and restructured (Bonß, 2013, p. 214).

That said, regarding the question of how individual action may influence the European social system, the following demonstrates how this constant challenge by unintended action might develop.

How can individual action make a difference to the ESM?

Building on Giddens' assumption that systems (including the ESM) are in permanent change due to individual action, the subsequent consideration in this context is the so-called 'chaos theory'. The reason for elaborating on this system-theoretical approach of sociology in the context of this thesis is that it is built upon the assumption that systems are not static but are constantly changing and evolving. The sociologist Luhmann (1992) translated the mathematical chaos theory into the field of sociology to explain unforeseen developments in societal systems. Contrary to Scharpf's assessment that the

Europeanisation of social systems is “*without a chance*” (Scharpf, 2002), Luhmann’s chaos theory shifts the question from whether it will ever be a realistic scenario to the question under which conditions it might occur.

His interpretation of the chaos theory suggests that the various societal systems are not self-sufficient but influence each other in their functioning (Küppers, 2000). Regarding the research question, this is highly relevant: While the ESM is enshrined in the ‘European Pillar of Social Rights’, it is far from being self-sufficient, but instead it relates to all kinds of policy areas. Likewise, while social policies have a substantial impact on disabled people’s lives (and disability has a substantial effect on the design of social systems), it is by far not the only relevant policy area.

It is, however, important to point out that the word ‘system’ in the context of Luhmann’s chaos theory does not refer to policy systems. In fact, the understanding of the word ‘system’ is used very differently in Luhmann’s sociological and Scharpf’s political assessment. On the one hand, Scharpf sees welfare systems as rather static set of legislative rules. Chaos theory, on the other hand, suggests that the current ESM is just a momentary projection within a dynamic process in which the European society constantly reorganizes itself (Küppers, 2010).

According to Luhmann, every system organizes itself according to its means. However, this is not incidental but based on causality. A slight change in this system thus causes further changes, which then again have their consequences, and so on. This is referred to as the ‘butterfly effect’.⁴¹ The ‘chaos’ that is name-giving to the theory thus does not appear due to apparent arbitrariness or human inability to restore order, but due to the complexity of infinite possibilities that a small change within a system may cause. While the name ‘chaos theory’ is somewhat misleading, it can be understood as projecting the missing predictability of a change in a system due to a single event or an individual action.

⁴¹ The name ‘butterfly effect’ derives from the US-American meteorologist Edward N. Lorenz, who in 1972 titled a speech “*Predictability: Does the Flap of a Butterfly’s Wing in Brazil set off a Tornado in Texas?*”

Regarding the research question, a first aspect that can be derived from this theory concerns the ESM as a framework for disability policies: One definition of the ESM, defined e.g. by Esping-Andersen (1999) and Ferrera (2001) contains the idea of the ESM being a 'perfect' social system that would cover all necessary aspects of society could be created, if only we could micro-manage every detail through regulating tools. From the point of view of chaos theory, this idea must be buried. That is because every regulation causes numerous other effects, which then must be regulated again, and so forth. Instead, according to chaos theory, there appears to be a paradox that, because of these (often unwanted) consequences of a change to a social system, every regulation contributes to the growing 'chaos', rather than minimising it. Federica Tosi (2010) has summarized this aspect quite accurately:

“Society cannot be assumed to be a static system, but rather an extremely chaotic system that is constantly rewriting itself and wandering on the edge of risk. Social systems are, with their phase transitions and tightrope walks, constantly at the mercy of falling into total chaos.” (Tosi, 2010, p.4).

This can, in fact, be observed in everyday politics: New legislation generally aims at reacting to a change of the given circumstances, the environment, or even to a change of society itself. It is thus considered 'good' if it maximizes the positive effects of that change, while at the same time reducing the negative effects to a minimum. A significant part of the work of disability lobbyists is therefore to convince political decision-makers of the positive effects that a certain change in legislation would bring, in a way that those politicians can justify the legislation before voters (experts 7, 8, 9, and 10). For example, the EDF's lobbyist (expert 7) who was interviewed for this thesis reported that the EDF's lobby work towards the Council consists mainly of convincing the national governments not to veto out their proposed changes in legislative proposals, that have previously been negotiated on with Members of the European Parliament and the European Commission.

From Luhmann's chaos theory point of view, the question of how much 'chaos' a specific change in legislation the respective legal system can endure before it collapses is the field of tension between conservative and progressive political

forces in politics. As for the ESM, the fear of unpredictable adverse effects often prevents changes to the existing social system. For example. The disability lobbyists reported a fear of mass immigration among representatives from member states with preferable or more advanced welfare systems, including disability systems (experts 7, 8, 10). It will be shown in Chapter 2.1.4 that this fear prevents the reform of existing EU legislation to prevent discrimination against disabled people.

Therefore, the question of whether a harmonised European social system could be established becomes a question of whether European society could handle all the consequences, both desired and unwanted, that this change would entail. Küppers (2010) emphasizes the need for adaptive forms of governance to capitalize on these constantly evolving situations.

Another aspect regarding disability that may be derived from chaos theory is that with growing support for self-determination and decreasing dependency on rigid disability systems, individual persons are increasingly able to decide on what actions they want to take. For example, suppose a disabled person who needs assistance is no longer bound to receive adequate services within the municipality where he/she is registered. In that case, that person can move to a municipality that is more appropriate for that person's needs. These actions could be taken outside the traditional social and disability systems, yet they might impact them. Following this strain of thought, it is important to remember that the actual impact of such a decision does not necessarily have to be intended⁴².

To illustrate this rather abstract idea, let us take the prominent example of Greta Thunberg, who at the age of 8 years learned about climate change for the first time, and in August 2018 decided to demonstrate in front of the Swedish Parliament with the famous poster 'Skolstrejk för Klimatet'. Nobody, including herself, could ever have predicted that she would cause a global movement that challenges almost all aspects of modern lifestyle, including a 'European Green Deal', a set of legislation aiming to foster sustainable industries and investments.

⁴² See **Fehler! Verweisquelle konnte nicht gefunden werden.**

While it was certainly Greta's initial goal to achieve some form of change towards more climate change, her example may also be used for the unintended impact of individual behaviour on a disability system: Greta has never hidden the fact that at the age of twelve, she has been diagnosed with the Asperger-Syndrome that is categorized within in the Autism spectrum. On the contrary, she even explained her outstanding interest in climate change with her being autistic. However, while her diagnosis has found attention by the media, she has not been seen as 'having a disability' or even 'in need of help'.

Under the assumption that individual action may cause such significant changes, while at the same time these 'chaotic' changes cannot be predicted, the follow-up question is how the effects of such individual action can be analysed. Regarding the research topic, this translates into the following: How have individual people (disabled and non-disabled) influenced the changing attitude towards disability in Europe in the past? To assess this question, chaos theory further explains the development of systems by the existence of so-called attractors⁴³. The idea is that seemingly nonlinear 'chaotic' systems build loops around reference points, creating temporary stability and order, which may differ widely from the original system.

While these loops are built through the repetition of behaviour, they can function as new 'standards' that have an organising effect. Regarding the research topic on living with disability in Europe, the interesting question is whether these attractors can reform the underlying value system on which European social and disability law is built upon. In the context of individual behaviour, the psychologists Syvantik and DeShon (1993) point out that "*many complex, seemingly random systems have attractors which define the system on a macro-level*", adding that "*systems which typically might be considered to be random will have such attractors defining them. This has been shown to be true for social systems as well as physical systems*" (Syvantik; DeShon, 1993, p. 340).

At this point, it is important to remember that the word 'system' in the sense of chaos theory cannot be used interchangeably in the context of the research

⁴³ Also referred to as 'strange attractors' or 'chaotic attractors'

question. While within this thesis, the terms 'social system' and 'ESM' describe a set of EU and national legislative provisions, Syvantik and DeShon use the term in the sense of social behaviour. However, under the assumption that social behaviour is the basis for legislative regulation, attractors are their predecessors.

To draw back the line to the research topic, the topic of institutionalisation in disability policies offers a good example of how attractors form. It used to be a common standard that disabled people were 'taken care of' in public institutions that had a hospital-like style. However, neither the organizational nor the value system included the idea that disabled people would have individual needs and wishes. Instead, those living in institutional facilities were expected to be grateful. As more and more disabled people eventually expressed dissatisfaction with this expectation, an attractor has been formed around the concept of self-determination. Once this had grown sufficiently, it fostered significant legislative changes, above all the UNCRPD. Today, according to one of their policy officers (expert 7), the deinstitutionalisation of disabled people is a key concern of the European Disability Forum. Additionally, it is permanently on the agenda of the Intergroup on Disability within the EU Parliament, as confirmed by its chairwoman (expert 3). Regarding the research question, this translates into an analysis of whether disabled people have taken steps, intentionally or unintentionally, that challenge the (at least partial) exclusion of disabled people from the European integration process.

There are, however, limitations to the applicability of chaos theory in this context. First and foremost, the fundamental purpose of sociology is to systematically analyse, understand, and explain the social coexistence of people. For that reason, social scientists traditionally assume continuous, linear developments that enable these analyses at the first place. Chaos theory, however, assumes non-linear action streams that limit the ability of drawing conclusions or making predictions (Maier, 1995). Furthermore, a key concern regarding the use of an initially physical science theory to explain social phenomena has been raised by Küppers (2012). According to him, it is impossible to prove whether social actions are non-linear and thus, chaotic. An

assumed non-linear action stream could, by its nature, never be proven. Therefore, he sees a scientific principle violated: the research's outcome must be verifiable. Consequently, statements that cannot be proved would be meaningless. Instead, he argues, all actions could, on the contrary, also be linear, even though we might not be able to comprehend the linear action in all its complexity. Because of this, he questions the added value of applying chaos theory in social sciences in general (Küppers, 2012, p. 248).

While his criticism is undoubtedly legitimate, it is precisely the added value that also serves as the main counterargument. Whether a stream of action is chaotic or linear in a complexity beyond our understanding is only relevant if the theory is to be used to replicate that stream. That is, as Maier and Küppers rightfully state, impossible. However, chaos theory helps to comprehend the potential impact of individual action on a system. Byrne (1999), for example, has applied chaos theory to explain patterns of inequality in social systems, such as healthcare or education, stressing that minor changes or events can have significant, irreversible consequences. Thus, the theory also helps to understand why significant societal changes are possible, including changes to the ESM that would include disabled Europeans.

Even Küppers acknowledged the added value of comprehending the scope of an individual's impact: "*chaotic systems (...) also represent an interesting model for the phenomenon of history. Because the processes that take place in such systems are neither reversible nor repeatable. They are just as unique as all historical events*" (Küppers, 2012, p. 228.).

A similar approach on how the chaos theory may be used has been proposed by the sociologist Bühl (1990). However, instead of a retrospective view of historical events he uses chaos theory to explain social change in general: "*chaos theory is of particular importance for the description and explanation of crises and transitional states in which either previously effective attractors suddenly increase or decrease in size, shift or disappear completely, or in which they lose their previously regular structure. However, the chaos theory is certainly useless to describe a permanent social condition*" (Bühl, 1990, p. 124).

This brings us to the value of chaos theory regarding the research question of whether the increasing focus on the rights of disabled EU citizens challenges the European social model. Chaos theory helps to understand how significant societal changes may evolve (e.g. Svyantek; DeShon, 1993; Lee, 1997; Elliot, 1997). The growing importance of the social model of disability and the subsequent claim for self-determination (see chapter 1.1) is such a change. It also helps to separate the question of *why* someone is acting the way he/she does from the potential impact of that action. As the following analysis of ECJ cases demonstrates, the individual's intention for action is an important, but not the only, criterion to be considered.

Therefore, while it does not enable the acquisition of knowledge of permanent statutes, chaos theory offers an approach to analyse transitional phases. Considering Küpper's criticism, it must be concluded that chaos theory cannot be used to achieve a desired outcome. The idea that a targeted change to the ESM or even the development of a European Social Union can be conjured up with the help of attractors must be ruled out. Nevertheless, concerning the social order, chaos theory has a destructive or destabilizing potential: The more non-linear action and thus, system-disrupting actions take place, the greater is the probability of potentiation and therefore, the formation of new attractors, without knowing in which direction this evolves⁴⁴.

In the context of disability, this disruptive power could (in theory) challenge the ESM. Whether it does will be subject to the second part of this thesis's analysis.⁴⁵ With this potential in mind, let us recall Edward Berkowitz's remarks on the reformability of disability programs⁴⁶:

⁴⁴ In world politics, there are many examples for this destructive potential. Terrorist actions such as those conducted by RAF or the Islamic State had far-reaching consequences in terms of security policies, debates about freedom of expression and religion, occasionally causing divisions in society. But: Both groups pursued specific goals that they could not achieve through such actions.

⁴⁵For that sake, a great part of analysis II (see section **Fehler! Verweisquelle konnte nicht gefunden werden.**) aims at assessing how 'chaotic' the current regulations in the three main areas (coordination of social systems, exportation of SSGI for disabled persons and Anti-discrimination) are, as well as the political will to decrease that chaos through harmonisation.

⁴⁶ See page 3

“Disability does not represent an exception to the general pattern of anachronistic and uncoordinated programs that are resistant to change. In disability, as in social welfare in general, the only avenue to fundamental reform is to add another program to existing programs and to cope with the resulting confusion.” (Edward D. Berkowitz, 1987)

The development of attractors may well be regarded as the addition of another program. However, prerequisites for reforming disability systems are problem-awareness and the political will to change this problem. Interestingly, the greater the confusion is in practice, the stronger the political will for harmonisation will be. In the context of the European Union, this may eventually result in a shift of competence from national to EU level. Whether this shift occurs may be observed with major reforms such as the ratification of the UNCRPD by the EU, as well as less extensive legislative changes such as ECJ rulings or reforms of national disability systems⁴⁷.

This interaction of individual action, the formation of attractors, and their influence on political systems is the interface to Eigmüller's research approach.

Citizens' rights as tools for social integration

*“Social integration still lags far behind economic and political integration. Substantial steps have been taken in recent years, particularly in enforcing individual rights in the context of the internal market and freedom of movement (...)”*⁴⁸

In her research, Eigmüller (2017; 2021) assesses the relationship between individual action and its effects on the social integration of the EU. Her research approach is based on mobility and the enforcement of citizens' rights in the context of freedom of movement. Based on an analysis of various cases brought before the ECJ, she concludes that individual claims of citizens' rights have driven EU policy towards more integration in the social field.

⁴⁷ E.g. the German “Bundesteilhabegesetz”, which aims at implementing the UNCRPD in Germany.

⁴⁸ Eigmüller, 2021, p. VI

The question to be asked regarding this thesis is whether Eigmüller's conclusion can be applied to social policies concerning disabled people. The hypothesis is that the successful enforcement of individual rights can cause a reciprocal effect in the area of disability policies. Once a specific right is manifested (and people claim to use it), it becomes the new norm, which can potentially affect our understanding of disability. This may be seen as the formation of an 'attractor' according to the previously outlined chaos theory.

It is a widespread view that the ECJ is the "*motor of EU [social] integration*" (e.g. Höpner, 2011; Vauchez & de Witte, 2013; Eigmüller, 2021). The logic behind that claim is that the ECJ manifests social integration into law by strengthening individual rights. For Eigmüller, it is the interplay of individuals and public institutions that is decisive for the analysis of European integration processes:

"In order to avoid normative assumptions and mere assumptions of causality, sociological research on Europe is forced to examine the specific dynamics behind this process of Europeanization in their interplay while at same time to readjust these observations theoretically " (Eigmüller, 2021, p. 5)

Regarding the field of disability, this interplay may be added by yet another aspect, which is the interplay of disabled private individuals and mainly non-disabled employees within the EU institutions. The more knowledge exchange and interaction take place, the greater changes in the understanding of disability itself, potentially fostering the integration process. The power of the ECJ to foster harmonization becomes apparent when considering the legal ambiguity for disabled people when traveling abroad. "*The vaguer the legal situation, the broader has been the scope for interpretation available to the ECJ and its case law*" (Shapiro 1994, p. 323). This vagueness not only applies to the actual exportability of entitlements but to defining disability itself, the concept of inclusion, and even the concept of non-discrimination.⁴⁹ Analysis Part II demonstrates how this conceptual vagueness translates into a lack of clarity in EU law.

⁴⁹ See "How EU institutions define disability", section. 1.1.3

For the reason of that vagueness in EU legislation, Eigmüller concludes that *“The basic paradigm of European legislation is thus case law designed by the ECJ, which is based on the principles of freedom of movement, non-discrimination and the self-realization of the individual”* (Eigmüller 2021, p. 19).

In other words, citizens' rights, or rather the enforcement of those rights, can serve as powerful tools for deepening European integration in the social field. For disabled persons, this is accompanied by an increasing self-perception of being entitled citizens with legitimate legal claims, rather than dependents.⁵⁰ Therefore, analysing the interplay between disabled individuals and the ECJ is crucial to comprehend the European social integration process. According to Eigmüller's evaluation of ECJ cases connected to social policies, the ECJ's past rulings have usually aimed to protect the national welfare systems. However, this came at the expense of the individual's right to move and reside freely within the EU. (Farahat, 2019).

Indeed, as early as 1984 Justice in a case concerning the supply of medicines the ECJ clarified, that *“community law does not detract from the powers of member states to organize their social security systems and to adopt, in particular, provisions (...) to promote the financial stability of their health-care insurance schemes”*⁵¹

This ruling has been remarkable for several reasons. First, although the case concerned the supply of products, the ruling included providing services without any distinction between these two economic sectors. Second, the ECJ connects social security systems with healthcare in its ruling. It is characteristic of the 1980s to view the need for care or assistance because of sickness. It is based on a medical approach focusing on treatment and, ideally, on curing the illness. However, because disabled people as well as elderly people in need of care do not (only) need to be treated, this approach often fails to fulfil the actual needs.

⁵⁰ See “What is disability?”, section **Fehler! Verweisquelle konnte nicht gefunden werden.**

⁵¹ Case 238/82 Duphar vs. The Netherlands (1984). To secure the financial stability of the national Ziekenfondsverzekering (sickness insurance fund), the Dutch government took measures to regulate the use of medicines as well as the export of medicines within the European Community, § 16

Furthermore, it is remarkable that the ECJ's main argument is not that healthcare, as part of the national social security system, remains within the member states' responsibilities⁵², but it explicitly named financial stability to confirm the states' power over organising their social welfare systems.

While the ECJ emphasises the financial burden of welfare for the member states, Eigmüller points out another obstacle for social integration: "*Social policy itself [has] a significant impact on the shape of society. Exactly this circumstance explains why the EU member states find it particularly difficult in this field to hand over competences to the [European] community*" (Eigmüller, 2021, p. 158). If the European social system was static, the research would end here. However, since the ECJ's ruling in 1984, various fields of social policies have been Europeanized to different degrees. Therefore, it is helpful not to see social integration as a yes-or-no question, but rather to acknowledge the various degrees of harmonization in the social field:

⁵² Later manifested in Art. 168 (7) TFEU regarding the provisions on public health

Degree of harmonization	Characteristic	Fields of social policy
Area excluded from Europeanisation	Excluded from Europeanisation according to EU primary law – however, not subject to national regulations within the member states.	Tariff rights (strikes, wages)
Area regulated by the nation-state	Exclusively national competences without national supranational provisions; Softening of national governance in relation to the group of benefit recipients	Means-tested social assistance (f. ex., social assistance, child allowances)
Open Method of Coordination (OMC)	Beginning harmonisation during “soft-governance”, however, without supranational provisions; beginning dissolution of territorial borders	Education, social security (e.g., pension, unemployment benefits)
Harmonized area	Acquisition/implementation of European law into national law without far-reaching dissolution of national frameworks; simultaneous development of equal rights in all member states	Anti-discrimination, occupational safety
Uniform socio-political area	Adoption of European law into national law; dissolution of national boundaries / cessation of institutional barriers between member states; preservation of member areas organised on national level.	Healthcare, patient mobility

Figure 10: Europeanisation of social policy according to degree of integration⁵³

The upcoming analysis, Part II, makes use of Eigmüller's degrees of Europeanisation as a scale to measure the integration regarding disability related policy areas, in particular the three interacting sub-areas of disability policies according to Halvorson, Waldschmidt, Hvinden, and Böhler (2017).⁵⁴ The goal, however, is not to describe the state of the art of where we are, but to identify the areas in which the changing perception of disabled people has been

⁵³ Based on Eigmüller, 2021

⁵⁴ see “The three Levels of Active European Citizenship”.

translated into European law and, more importantly, how this change has occurred. The analysis is based on the assumption that social systems, including the integration of disabled people, are indeed not static, but adapt to people's needs. Consonantly, the question shifts from whether disabled people can exercise their rights when moving from one existing system to the other, to the question of how the relevant systems adapt to the changed way of thinking about disabled people.

In a larger context, the example of support for disabled people shows that the integration of social policies is possible. At the same time, it is acknowledged that this does not mean that the result of this integration process will necessarily be the extension of a harmonised system on the European level, but it could instead form a completely new system of regulations and values.

The chapter addressed the potential impact of individual action on a value system, such as the European approach to disability. Prominent sociologists have argued that there is an interplay between individual action and the value structure behind organizational systems. Therefore, if collective values change, as does the understanding of disability, so do the actions – and vice versa. The increasing claim for self-determination of disabled people represents such a changing value. Luhmann's interpretation of the chaos theory is one way to illustrate the potential impact of individual action. He illustrates how repeated individual action can establish so-called 'attractors' that build the cornerstones of a new organizational system.

In the context of EU social policies, Eigmüller assessed the relationship between individual action and its effects on the integration of EU social policies. According to her studies, because social policies are not within the scope of the EU's regulatory competences, critical legislation in this field tends to represent the lowest common denominator. This often results in vague formulations in EU law. As the upcoming analysis in Part II will demonstrate, this can also be observed in legislation concerning disabled people, such as anti-discrimination, the coordination of social security, and the exportability of SSGI. When an individual person claims his/her citizen's rights based on this legislation, it is up to the ECJ to decide how the respective legislative act is to be read. Eigmüller's

research has shown that in the past, the ECJ has repeatedly ruled in favour of strengthening citizens' rights. Thus, individual citizen who enforce their citizens' rights can be a powerful factor to promote the integration process in the social field. This thesis contributes to this research by analysing whether the same mechanism applies to the field of disability and whether enforcing the right to self-determination accelerates this process.

1.2.2 Why disability interest groups are different

Having laid out the theoretical ground on how individual action can impact the ESM, the following chapter will analyse the pre-political factors. We start with the framework in which disabled people can advocate their interests, including their interests concerning free movement within the EU.

The guiding question for this chapter is: Are disabled people able to express their interest in EU politics, especially recalling the difficulty in defining the group as explained in chapter 1.1? How can a common interest be formulated within a group that is (by definition) heterogeneous? The relevance to the research question derives from the assumption that the political changes, which are analysed in Part II, are only fostered when a pre-political force actively expresses the need to act.

Next to Washington D.C., Brussels is particularly famous for the density of lobbyists, cumulating to roughly 2.500 lobby organizations that are physically present in the Belgian capital. Their influence is undeniable and has even been portrayed by a movie⁵⁵. In this environment, the apparent question thus is: Are European citizens who are disabled in exercising their right to move and reside freely within the EU able to organise themselves on the European level and actively lobby for a change?

In this thesis's context, the relevance of a pre-political force lies in the consideration that a change in the exportability of disability-related benefits such as SSGI could potentially impact the entire ESM of separate national welfare systems (as laid out in the previous chapter). Due to this potentially macro-

⁵⁵ "The Brussels Business" (2012) by Friedrich Moser and Matthieu Lietaert

political impact, it is appropriate to place the following analysis in a macro-sociological context: the relationship between power dynamics and politics.

When analysing power dynamics, one cannot neglect the classic debate between Michael Foucault's discourse analysis and Jürgen Habermas's concept of communicative action (e.g. Allen, 2009; Haus, 2023). The common understanding of their academic work assigns Foucault a focus on societal power dynamics that significantly influence strategic actions in policy-making processes. While exceeding the scope of this chapter, an earnest application of Foucault's discourse analysis would provide a much better definition of power. However, it is fair to assume that in the context of lobbying in EU policymaking, most people would allocate those who permanently depend on some form of social assistance and are partially deprived of their rights as European citizens (in many cases even their right to vote⁵⁶) to the lower end of that power scale. In the case of disability, this is even supported by Foucault's concepts of "*bio-power*" and "*bio-politics*", which link politics to individual biological features (e.g. Tremain, 2005; Sullivan, 2005; Marks, 2008). The underlying idea is that power is exercised by the expectation to act in the interest of society. Based on this assumption, "*biopower is concerned with the statistical analysis of vital processes – birth rates, longevity, accidents, illnesses, morbidity – that occur within the population*" (Marks, 2008, p.46). Therefore, the less healthy a person is, the less he/she contributes to society, and the more he/she relies on society to cover potential costs. This results in a loss of power and thus, the ability to lobby.

On the contrary, Habermas assumes that critical praxis occurs in consensus-oriented communicative actions that are not limited by power structures. Instead of power being derived from expectations to act in the interest of society, he argues that power is constructed and depends on the respective circumstances (Finlayson, 2005, p.40 ff). Unlike Foucault, Habermas' theory would therefore allow active participation of (severely) disabled people in shaping politics that does not depend on economic power in the sense of sales figures and the

⁵⁶ In its opinion SOC/638/2020/EESC the European Economic and Social Committee describes the legal and technical obstacles preventing disabled people from participating in the European elections.

number of employees. This communicative action, however, requires an ongoing exchange between disabled people and policymakers.

Consequently, analysing the pre-political force requires an assessment of who engages with policymakers on the one hand and an assessment of the power they can exercise on the other. Alongside the questions to be addressed are who considers themselves to be disabled, ill or simply outside the assumed norm, who has formed a lobby group and who has not, and who depends on others to advocate on their behalf due to the nature of their impairment or health status?

Furthermore, when analysing the disability lobby in Brussels, it is important to understand the difference between social interest groups and their potential adversaries. Thus, before diving into the analysis on the actual (self-)advocacy structures, the following paragraphs identify two factors that distinguish disability lobby groups from the majority of the 2.500 organizations. On the active side, those are the specific characteristics of disability interest groups (chapter 1.2.3). On the other hand, the factor to be considered is how prejudices about disabled people influence the power dynamics vis-à-vis the communicative action between disability lobby groups and policymakers (chapter 1.2.4).

After identifying the organizational structures of lobby groups in the disability field and the difficulties they face, the subsequent chapter assesses the access to policymakers and the framing of the exchange between them and disability lobby groups. The findings of these first two sections mark the independent variable. The effect of these pre-political factors is generally measured by how the perception of disability has changed on the European level and, in particular, how the discourse has changed regarding citizens' rights and freedom of movement. In that sense, chapter 1.3 forms the dependent variable to evaluate whether there is an active pre-political force that promotes freedom of movement for disabled people.

The political sociology of social disability interest groups

This paragraph uses three pillars that form the political sociology of interest groups to examine if and how social interest groups can hold their ground in a political sphere shaped by numerous, mainly business-oriented lobby organizations (Scott, 2018). Those are:

- the reason why an interest group is formed,
- their influence on political activity and policy, and
- the relationship of power and inequality.

The key difference in the formation of social movements and citizens' groups is that they (unlike other lobbyists) often “*seek changes outside the institutionalized system of decision making*” (Scott, 2018, p. 18). In many cases, this results from the group's aim of changing the system, or at least parts of it, itself. Consequently, it may not be feasible to act according to the rules of a system that they are seeking to change. However, participating in the institutionalized processes and fostering changes to these processes by other means does not have to be exclusive. Popular examples of this dual strategy are organizations such as Greenpeace, Amnesty International, and Transparency International. On the one hand, they are registered in the European transparency register and engage in policy-making processes through public consultations and the publication of opinions; on the other hand, they pressure decision-makers through media-effective, sometimes illegal actions. In democratic policy processes, it is appropriate to question the legitimacy of these actions outside the established policymaking systems, especially when purposely violating the law.

At that point, however, a second key difference is to be considered: Rather than advocating their own interest, these interest groups are formed to achieve some form of collective good and thus, an improvement of the system itself. Therefore, “*it makes sense to differentiate between lobbying and protest groups by the level of institutionalization of the group. That is, how much is the group a part of the formal political or policymaking process?*” (Scott, 2018, p.18). As demonstrated in chapter 1.2.4 and confirmed by lobbyists interviewed for this thesis (experts 7,8, 9, and 10), advocacy groups for disabled people are far from being protest groups, while at the same time seeking changes to the

(social) system. Using Scott's definition, it is debatable whether lobby organizations in the disability field can be described as social interest groups, given that they foremost represent their interests. On the other hand, the number of affected people that these groups represent may (depending on the subject) sum up to about 10 % of the entire population, which can very well be considered a public interest.

As for the second aspect of influence, the apparent difficulty concerns the measurement of successful lobbying. While there are undoubtedly different lobbying strategies, *"the strongest effects of interest group influence are likely felt at the stages of policy-making that are least visible, such as when decision agendas are formed or when legislation is drafted"* (Scott, 2018, p. 13). This has been confirmed by the interviewed disability lobbyists (experts 7, 8, 9, and 10). For example, the EDF (expert 7) organises the meetings of the disability intergroup at the European Parliament, chaired by MEP Langensiepen (expert 3), including the agenda-setting.

Scott's approach to measuring influence based on the policy agendas or legislative drafts is promising because it enables an analysis of successful lobbying by investigating changes in the political agenda. For that sake, chapter 1.3 elaborates on how European agendas in the disability field developed over the two decades before this thesis regarding citizens' rights and free movement. However, this approach has the obvious limit that *"influence is often not visible to the scholar or citizen except in the rare instance of an actual change in policy or the clear defeat of a proposal"* (Scott, 2018, p. 13). In that sense, the scale for successful lobbying by disability groups cannot simply be the actual impact of legislative acts on the individual, but whether these groups can promote problem-awareness among policymakers and the political will to change the existing system.

Nevertheless, while financial resources and the number of professional employees are insufficient for measuring successful lobbying, they cannot be ignored as indicators of a lobby group's means, bringing up the third aspect of the relationship between inequality and power. Most (social) lobby organizations in the disability field are funded entirely or by a significant amount through

European Funding tools. While this enables them to operate independently from their economic success, it is also the clearest dependency on the European institutions, particularly the European Commission. Some of the experts interviewed for this chapter have been remarkably careful when criticising the European Commission's action to the extent that some answers, for example, concerning access to policymakers during the COVID-19 pandemic, had been held back after the record. They report difficulties in making themselves heard in Corona times, especially in policy fields that are not explicitly designed to target disability-related issues, but that affect them indirectly.

Furthermore, recalling the variety and degrees of possible disabilities, the question of who represents disabled people is an important component of their lobbying work. Considering that another important element in lobbying is physical presence (Scott, 2018), self-advocacy becomes impossible for non-Belgian EU citizens whenever their assistance services are not exportable to Brussels. In these cases, the inability to move between the EU member states prevents them from advocating their interests, including their interests regarding freedom of movement. The option left is to delegate the representation to professional lobbyists who do not depend on social assistance services or whose needs can be met by Belgian service providers, manifesting a selection bias in lobby groups. This imbalance of who is physically present in Brussels is demonstrated by the upcoming analysis of the organizational structures (chapter 1.2.4). The argument can be made that physical presence is becoming less important in an increasingly digital environment. However, many electronic devices or digital meetings are not accessible to disabled people for a variety of reasons, again marking a selection bias. As experts 7 and 10 pointed out, unlike physical presence, digital lobbying requires an invitation by the event hosts to participate in discussion panels. This has two effects: First, it increases the lobbyist's dependency, and second, it strengthens their 'special role' as disabled people because they are invited as such.

1.2.3 Self-advocacy groups and the European Disability Forum

Considering the dynamics of social interest groups (chapter 1.2.3) and the difficulties that disabled people (or their representatives) face when interacting

with non-disabled people, the guiding question for the subsequent analysis is: Who represents disabled people in EU policy-making processes?

Since the 1990s, the slogan “*nothing about us without us*” has become increasingly popular and is now known even by many who are not directly affected by disability policies (Reyes; Inglesias, 2023). It reflects the idea that no policy, in particular disability policy, should be decided without direct participation by those affected by the policy. Thus, the question of who represents disabled people in EU politics is also about the possibilities for self-advocacy in the Brussels sphere. Therefore, the analysis of this chapter focuses on who is present in Brussels and actively engages in policy-making processes.

While providing a picture of how disability-related lobbyism is framed in Brussels, the approach is limited, not least due to the difficulty in defining disability, which has previously been explained in chapter 1.1. As the following analysis demonstrates, the same problem of defining disability is projected on how disabled people are engaged in EU policy-making processes. An example of this is, among many others, long-term patients of Multiple Sclerosis, who may be disabled in several areas (including their ability to travel), but who might be categorized in the health sector by many authorities. For this reason, this chapter does not claim to be a complete list of all the stakeholders involved.⁵⁷

When analysing ‘us’ in the slogan’s sense of disabled people, it is important to remember that not all stakeholders in disability politics share the same interest. This may result in power struggles about which issues are to be put on the political agenda. While, for example, physically incapacitated people have a strong interest in prioritizing accessibility issues, they may not experience substantial barriers in exercising their citizens’ rights, especially those who are economically active. On the contrary, people with intellectual disabilities are, in many cases, even deprived of their voting rights, making fighting this form of discrimination a key interest.

However, a second dividing line among the stakeholders is to be considered, namely between social service recipients and their providers. Essentially, it is

⁵⁷ For that sake, the European Multiple Sclerosis Platform (EMSP) and the AGE Platform Europe which represents citizens above the age of 50 are not included in the analysis.

the social services equivalent to the first sector's power struggle between economic interests on the one side versus consumer protection on the other. In other words, as a lobbyist from Social Economy Europe pointed out, the interests of disabled people may very well conflict with the interests of social service providers (expert 9). As for this thesis' topic of free movement, the potential conflicts of interest are apparent: While on the one hand, the non-entitlement for certain services may inhibit the individual person from exercising their rights as European citizens, the actual utilisation of those services by foreigners is not without challenges for the service providers. They reach from different expectations about the scope of the service, the refinancing of their costs (including their employees) by foreign authorities, the needs assessment (both in terms of quantity and scope), to simply unsolved language barriers with the recipient or their responsible public authority. A real case example for these challenges has been described by a manager of a German facility who has admitted a Belgian resident with multiple severe disabilities (expert 14).⁵⁸

Additionally, unlike regular markets, social businesses in the social services market face an additional challenge: they cannot simply turn down a client whenever they feel that they cannot provide the services according to the person's needs. Social services are financed by public means, meaning either the service provider is (at least partially) state-owned or their economic efficiency depends on a service contract with the respective authority. In most cases, those service contracts obligate the social company to provide services to all disabled people who live in the respective territory. This may include those from abroad, if they reside legally within the host member state.

For that sake, it is important to understand not only if and how disabled people can advocate their interests regarding free movement but also *who* represents them. The data from the official EU transparency register is used to address this question.⁵⁹ The results are filtered to those organizations that actively engage in EU disability policies and hold an office in Brussels:

⁵⁸ See chapter 3.3: Beyond the European Social Model: A best case example

⁵⁹ data retrieved April 2021 from: <https://ec.europa.eu/transparencyregister>

Lobby Group	Goal	Number of members	Number of full-time employees
European Disability Forum (EDF)	Advocating for the inclusion of all persons with disabilities in the EU. According to its presentation, the EDF “ <i>defends the interests of over 100 million persons with disabilities in Europe.</i> ” (EDF Website, 2021)	102	14
Inclusion Europe (IE)	European association of people with intellectual disabilities and their families. providing information in easy-to-read language on the legal situation in the EU member states and on political developments in the field	79	2,8
European Network on Independent Living (ENIL)	Disability movement for human rights and social inclusion. Key issues are solidarity, self-determination and self-representation, deinstitutionalisation and mainstreaming of disability (also called cross-disability)	72	2,2
Autism-Europe (AE)	Advancing the rights of autistic people and their families by awareness-raising and fostering a better policy response to the needs of autistic people	90	4,5
European Union of the Deaf (EUD)	Recognizing the right to use indigenous sign language, empowerment through communication and information, equality in education, and employment.	32	5
European Union of the Deaf Youth (EUDY)	Fostering social and political participation of young deaf Europeans through non-formal training and youth exchange programmes, improving access to education and employment	30	1,5

Figure 11: Groups representing the interests of disabled people

Remarkably, all registered organizations are so-called 'umbrella organizations', meaning that they do not represent the interest of a single company, but the combined opinion of an alliance of stakeholders. This organizational form has several advantages: First, the platforms have a greater political weight due to the sheer number of people they represent (see e.g. Coen, 2007; Treib; Falkner, 2009). The EDF even claims to represent the interests of more than 100 million people, roughly a quarter of the entire EU population. Second, the various interests and opinions are channelled before policymakers are addressed, enabling targeted policy proposals for changes in legislation or action by the EU institutions. Additionally, these umbrella organizations function as platforms to exchange best practices and information on policy developments (ibid.).

However, there are also disadvantages. As in every group, the larger it grows, the more difficult it becomes to reach a consensus. Just as ordering food at a party becomes a real challenge as more hungry people express their wishes on whether to order Pizza, Sushi, or Durum, it becomes increasingly complex to form a common opinion on political issues, the more an umbrella organization grows in the number of members it represents.

This problem becomes even more significant when considering that next to these 'direct' representatives, there is another group of organizations that have organized on a European level and claim to 'indirectly' represent the interests of disabled people: European lobby organizations of service providers for disabled people. While most of these groups, such as the European Social Network (ESN), represent a wide range of service providers, the biggest European network by number of member organizations is the previously mentioned EASPD. This group defines its primary objective as *"to promote equal opportunities for disabled people through effective and high-quality service systems"* (expert 9). Some organisations are ecclesiastical, such as the evangelic Eurodiaconia. Additionally, some groups are specialised service providers, such as Mental Health Europe (MHE), representing psychiatric institutions and mental hospitals.

Name of Lobby Group	Goal	Number of members	full-time employ.
European Association of Service Providers for Persons with Disabilities (EASPD)	Representation of the approximately 11.000 service providers for disabled people. Key topics are the right to work, inclusive education, independent living, financing of social services and person-centred technology.	130	2,8
European Platform for Rehabilitation (EPR)	Network of service providers to disabled people. Monitoring of EU disability policies and providing policy analysis for their members.	25	0,2
European Social Network (ESN)	Strong social protection and welfare systems, accessibility of public and social services	47	10,8
Social Services Europe (SSE)	Representation of not-for-profit social & healthcare service providers. Key topics are SSGI, the role of service providers, public procurement, state aid and social innovation.	7	0,5
Mental Health Europe (MHE)	Representing the professionals and service providers such as psychiatry institutions and mental hospitals. However, also advocacy for mental health service users and persons with psychological disabilities. Key topics are human rights in recovery approaches, community-based care, equal valuing of mental and physical health	80	5
Eurodiaconia	network of 52 churches and protestant social and health care service providers. General aim to improve social services, including those for disabled people. Also active in fighting poverty, youth work and social and economic policies.	52	9
Platform of European Social NGOs / social platform	network of civil society organizations advocating for a social Europe	47	8

Figure 12: Relevant groups representing the interests of service providers for disabled people

The distinction between organizations directly representing the interests of disabled people (and thus the receivers of social services) and the providers of these services is important. While in most cases it is fair to say that both sides are eager to form a joint position to speak with a stronger voice to policymakers, in some cases, their positions can be contradictory. A prominent example is the issue of deinstitutionalizing the provision of services for disabled people. While the service recipients of these services have a strong interest in inclusive service provision outside separated institutions, these institutions are often the main business segment of service providers, which cannot simply be dismantled without an alternative replacement. Recalling the topic of this thesis, the providers of social services have little to no interest in fostering cross-border mobility of disabled people, as it offers no advantage to them but constitutes potential challenges, for instance, along language barriers between employees and service recipients. Therefore, lobby organizations representing the providers of social services could find themselves in a quandary between advocating the interests of their clients and their own economic and operational interests.

Where all come together: The European Disability Forum (EDF)

In disability policies, whenever it is possible to reach a common opinion, it will be promoted by the European Disability Forum (EDF). It is, without doubt, the flagship of disability advocacy in Brussels, not only due to the number of member organizations (102) and the number of full-time employees (14) but also because most other disability platforms are full members of the EDF. Most of their members do not hold their office in Brussels⁶⁰. Instead, those organizations are granting the EDF the right to speak on their behalf. Other EDF members, however, are physically present in Europe's capital. Compared to the EDF, they have a more detailed focus, e.g., representing solely the interests of autistic persons or those with intellectual disabilities.

Interestingly, the EDF's list of members also includes service providers such as EASPD, national organizations, and observers in and outside the EU.

⁶⁰ e.g. the European Blind Union (EBU), European Deafblind Union (EDbU) or the European Down Syndrome Association (EDSA) are not registered within the European lobby register, but channel their interest via the European Disability Forum

Thus, the opinions published by the EDF can be regarded as the lowest common denominator on which most disabled people and the operating service providers can agree. Accordingly, the EDF's opinions and statements are given significant weight when assessing the lobby activities in the disability field in Brussels.

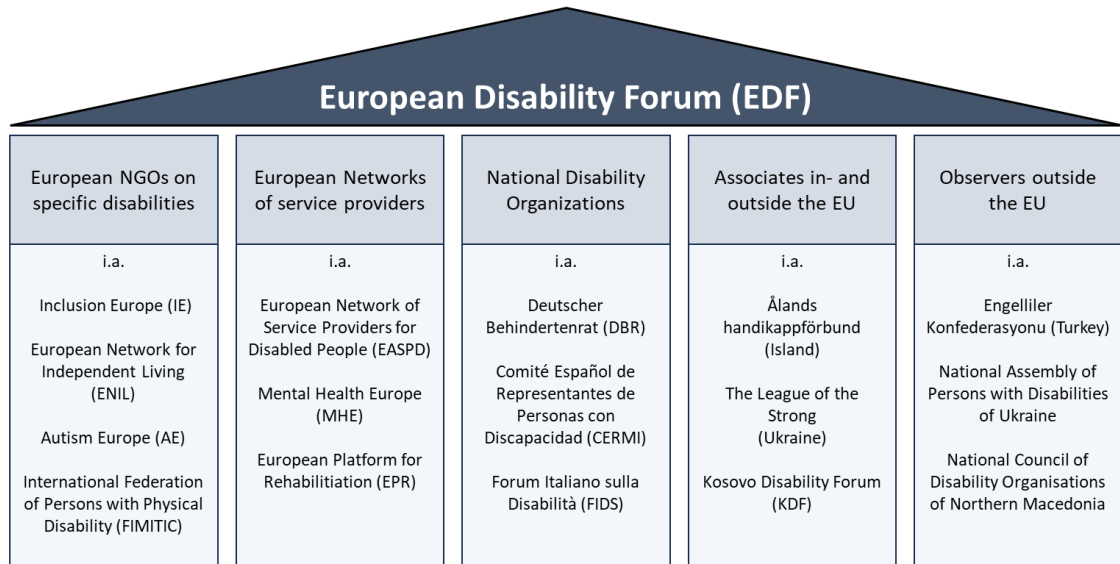


Figure 13: Organization of disability lobby groups in Brussels under the EDF umbrella⁶¹

On the one hand, however, the central role of the EDF and the number of rather specific organizations also demonstrate that there are often different, occasionally contradicting interests at stake. In those cases, the organizations may publish separate statements.

Concerning the free movement of disabled people, dividing lines exist, e.g., between the EDF and the European Union of the Deaf (EUD). Whereas in other disability fields, the impairment may at least partially harm the person's employability, for deaf people, it is often simply the loss of eligibility for a sign language interpreter. For that sake, the EUD has published a separate statement on the issue of freedom of movement for economically active deaf people in Europe.⁶²

Another dividing line between the EDF members concerns the prioritization of topics. While for some groups, the topic of freedom of movement should be high on the agenda, it plays only a marginal role for others. As for Inclusion Europe,

⁶¹ Based on members list retrieved April 2024 from <https://www.edf-feph.org/our-members/>

⁶² Retrieved April 2024 from <https://eud.eu/eud/position-papers/freedom-of-movement/>

an organization that focuses solely on the interests of people with intellectual disabilities, the discussion on whether disabled people are deprived of their citizens' rights to move abroad is almost cynical, considering that many people with intellectual disabilities are not even granted their right to vote in the European elections. In contrast to the EUD, Inclusion Europe engages in policymaking whenever possible, often teaming up with the European Network on Independent Living (expert 10). However, they do not publish their opinions outside the EDF.

For other groups, the need for action has a more direct impact than citizens' rights, so they tend to overlook topics such as citizens' rights and free movement in favour of pushing more pressing issues onto the political agenda. For example, the European Union of the Blind focuses intensely on the rules for the development of electric cars, which increasingly disable blind people from safely navigating road traffic due to the lack of engine noise.

Remarkably, one group appears not to be self-represented through its lobby organization, which is those who experience disability because of psychological diseases or impediments. Their interests are only partially represented by an organisation that represents psychiatric hospitals and other service providers called Mental Health Europe (MHE). The expert interviewed for this thesis made clear that for MHE, the issue of moving between member states has no significance. Instead, in MHE's professional sphere, the term 'freedom of movement' is used in the context of urgent self-endangerment, when patients might temporarily be tethered to their beds (expert 8).

1.2.4 How disability advocacy groups can access European policymakers

Lobbying for social interests is somewhat unique in the way that it is characterized by finding consensus. For that the focus is put less on the actual legislative act, but rather on setting social standards and bringing certain topics onto the policy agenda (Treib; Falkner, 2009). Thus, having briefly outlined the difference between social lobby groups in the disability field and other lobby organizations, the following paragraph is dedicated to the other side of the relationship essential for advocacy to succeed: the side of decision-makers. In other words, even when the various, occasionally opposing stakes of disabled

people are channelled, well-formulated, and brought to the attention of legislators, they might not make it onto the political agenda because of the severe obstacle of stigma on the receiving end. This experience has been verified by experts 7, 8, 9, and 10. Therefore, analysing how the aforementioned lobby groups can operate must include the difficulties they face due to misconceptions, prejudices, and stigmatization.

To assess this aspect, the following paragraph builds upon the thoughts by the sociologist Cloerkes (2014). He has formulated the core of the problem of inconsistent norms in the social reaction towards disabled people: *“the norms are contradicting, and this leads to forms of social reaction, which are superficially acceptable and promise the relief of insecurity. However, in fact, they cause rejection and social isolation of disabled people”*⁶³ (Cloerkes, 2014, p.122).

The key aspect of this contraction is the assignment of liability and guilt, which forms a reference value for the design of social policies. Especially long-term unemployed persons are given at least partial blame, in many cases even suggesting the malicious intent to live off the hammock of the social welfare state. The same blame is also projected on disabled people whenever their impairment is regarded as the result of a lifestyle choice (e.g., heavy obesity, accidents while practicing hazardous activities, or even long-term effects from alcohol abuse). The assignment of guilt in these cases ‘justifies’ the unequal treatment.

However, in general, disabled people are discharged of the responsibility for their situation, thus making the same discriminatory measures illegitimate. According to Cloerkes (2014), this problem is bypassed by assigning a special role to disabled people, which is formed by assumptions about their needs, their capabilities, and most significantly, their inabilities. This has two effects: First, assigning a special role enables non-disabled people (including EU legislators) to encounter disabled people in a special way, which is not necessarily on an equal level. In this context, sympathy towards disabled people is a form of lived, socially accepted superiority. The second effect defines this special ‘disability

⁶³ Translated from German

role' by characteristics of inferiority, leading to social isolation. Even further, it is up to the non-disabled to define the appropriateness of the measures taken to encounter this social isolation.

Cloerkes has formulated the severity of this aspect as such: "*The stigmatization and separation of deviants have a stabilizing function for the social system [...]. The existence of the role of the sick and the role of the disabled is impressive evidence of the functioning of system-stabilizing control mechanisms*" (Cloerkes, 2014, p.125)⁶⁴.

In other words, stigmatization not only leads to a lack of knowledge about the needs of disabled people, but it may even form misguided assumptions on which the social systems themselves are built. Prejudices enable the imposition of separate roles, including a special disability role, which is essential for the maintenance of the ESM that (inter alia) prevents many disabled people from exercising their EU citizens' rights.

Bringing Cloerkes' thought in the context of disabled people's right to free movement in the EU, the fact that disabled people cannot exercise this EU citizens' right equally with others reflects the fear that deviant persons threaten the national social systems. The control mechanisms, which stabilize the ESM, are stigmas about disabled people's economic performance, their health status, and sometimes also their intelligence. The performance value is enshrined in EU law concerning free movement by tying this right to economic activity. The 'special disability role' justifies (socially and legally) the discriminatory regulations regarding free movement.

This is the contradiction of liability and discrimination: "*official discharge from liability and guilt, on the one hand, factual discrimination, and stigmatization with the assignment of a special, deviating role on the other*"⁶⁵ (Cloerkes, 2014, p. 133 f.). The topic of this thesis is a good example of this correlation. Common unfiltered reactions in the author's professional, academic, and private environment when describing the research field included remarks such as "*don't they have other problems to deal with than moving abroad? Don't you think that*

⁶⁴ Translated from German

⁶⁵ Original in German

many of them do not have the capacities?" or *"do they even want to go abroad?"*. While those remarks are not representative, they are valid questions regarding the relevance of this research. However, they also imply prejudices about disabled people's quality of life, their intelligence, and ultimately their mental ability to make their own decisions. At the same time, the need to change the current ESM is being questioned.

In the context of EU lobbying, the same reaction may hinder lobby organizations from being successful (e.g. Coen, 2007). Not only can prejudices among decision-makers result in a lack of political will, but the prejudices may even be ostensible (but welcomed) reasons why decision-makers do not see the need to change the existing systems, or the coordination of social systems. For that sake, a significant part of disability lobby work aims at establishing disability as a normality in society that should be included in all political aspects, rather than viewing disability as a special role (experts 7, 8, 9, 10).

On the contrary, however, previous research suggests that many people are questioning the need for further research in this field, resulting in a so-called *"research fatigue"*. (Cloerkes, 2014, p. 121). While this might be true for traditional academic research, awareness-raising campaigns on including disabled people have significantly increased, not least through the UNCRPD (Sturm et. al., 2018). The more this information on disability is available, the more the 'traditional' stigmatization of disabled people is challenged, and thus, the social systems that are in place.

The access of disabled people to European policymakers

Having identified who represents disabled people and service providers for disabled people, the subsequent question is what the chances are for these organizations to have an impact on policymaking processes. All these organizations publish opinions and position papers on political issues of their concern. However, how can they ensure that these papers are being read and policymakers are hearing their opinions? To answer this question, the interview partners for this thesis from disability lobby groups (experts 7, 8, 9 and 10) have been explicitly asked what lobbying means to them and who they can address in their daily work.

While there are some differences between the organizations, all interviewed experts reported that there are formal and informal ways. The first named option was participation in public consultations launched by the European Commission. This process is commonly open to all EU citizens and organizations. The interview partners reported that these consultations are important milestones in their work and serve as funnels to establish common opinions on specific issues within and between the organizations. As laid out before, the EDF can be seen as the alliance of all groups, giving its voice the highest weight. Nevertheless, in some cases, their opinions might contradict. For example, access to personal assistance is essential to the European Network for Independent Living (expert 10) but has little relevance for Autism Europe or Mental Health Europe (expert 8). Thus, the organizations cannot always rely on the EDF's weight on specific issues. Additionally, the interview partners pointed out timing as a second problem regarding participation in public consultations. In most cases, the Commission launches public consultations after it has already worked out its first draft for a new piece of legislation. Thus, the respondents are limited to a reactive role, rather than being an initiator for specific issues.

This brings us to another formal way of disability lobbying at a very early stage: The UNCRPD has led to a higher visibility of disability organisations at the EU level (Sturm, et. al., 2017). Most notably, the European Commission established the so-called 'High-level working group on disability' in 2006, an expert group whose task has been to advise the European Commission in drafting disability-related policies. This group included five NGOs, two of which were the European Association of Service Providers for Persons with Disabilities (EASPD) and the European Disability Forum (EDF)⁶⁶. Other Members included representatives from all member states. Interestingly, the country with the most delegates has been Belgium, which is likely to be connected with the different disability systems and approaches of the Belgian regions (Wallonia, Flanders, and the German-speaking region around Eupen). The High-Level Working

⁶⁶ The remaining three were the European Platform for Rehabilitation (EPR), the European Women's Lobby (EWL) and the Confederation of Family Organizations in the European Union (COFACE)

Group also included a disability division of the Council of Europe and representatives from Iceland and Norway. Its mission has been “to establish close cooperation between the institutions of the member states, the Commission and the civil society on issues relating to disability and to facilitate the exchange of information, experiences and good practices”⁶⁷. However, in 2019, the High-Level Working Group was dissolved.

Due to the COVID-19 pandemic, it took almost 3 years to set up a successor, until eventually, in December 2021, the so-called Disability Platform⁶⁸ was found. On the initiative of the European Commission, the platform is much bigger than its predecessor. Next to delegations of two representatives from each Member State, 17 NGOs have been invited to participate, including all of the aforementioned disability-related lobby groups. Not only is the constellation different from its predecessor, but the work structure also differs. The Commission organises formal meetings every 3 to 4 months, where the stakeholders have a regular chance to bring forward their positions on specific issues. As the policy officer of ENIL (expert 10) reported, these meetings are of great importance for their lobby activities, because they enable the stakeholders to know about upcoming legislative activities even before the first proposal is published. Additionally, not only are the stakeholders' position papers being released during the first drafting of policies, but they are also often directly forwarded to the European Commission.

At this point, individual people (in the proper position) can indeed have a significant impact, as the delegations within this expert group consist of only two people each. For example, when drafting the European Disability Card⁶⁹, the representatives of ENIL brought forward the notion to include personal assistance in the directive. Even though the notion has eventually been excluded from the directive's scope, it initiated a debate among the present representatives of the member states, who (according to expert 10) admitted not to know about the problems regarding personal assistance within their home

⁶⁷ Commission's [Website](#) on High Level Working Group on Disability, last updated October 15th, 2020

⁶⁸ Commission decision [C\(2021\) 7591 final](#)

⁶⁹ See Chapter 2.3.3

states and asked the NGOs to support them with data gathering their expertise to improve the situation domestically.

Similar to the disability platform organised by the European Commission, the European Parliament has formed the so-called 'disability intergroup' in 1980. While this group has no formal legislative powers, it is equally important to the disability lobby groups to ensure access to the MEPs. The intergroup is chaired by MEP Katrin Langensiepen (expert 3), who also been interviewed for this thesis. She highlighted the intergroup importance by pointing out that not only is the intergroup organised by the European Disability Forum (EDF), "*the EDF also usually sets the agenda for the intergroup's meetings*" (expert 3).

The policy officers of ENIL and the EDF (experts 7 and 10) confirmed the intergroup's importance regarding access to MEPs and provided an example of how this access can have a real impact: On October 11th, 2023 the EDF's Vice-President Gunta Anca met the European Parliament's rapporteur for the European Disability Card MEP Lucia Ďuriš Nicholsonová (See chapter 2.3.3). In a public statement, Ms. Nicholsonová showed great respect to the EDF's work: "*My intention as rapporteur is to urgently negotiate quality legislation that will (...) facilitate their freedom of movement (...). I look forward to working closely with the EDF on this important legislation for persons with disabilities.*" (Felix, 2023).

During the meeting, the EDF stressed its positive reception of the Commission's legislative proposal but pointed out that from the EDF's point of view, certain aspects of the proposal such as the universal recognition of the disability status were more important than others. Thus, the organization's key intention was that the Commission's initial proposal would not be 'downgraded' during the negotiations between the European Parliament and the Council that were about to follow. This was confirmed by a representative from the Bulgarian delegation to the Council who was involved in these negotiations (expert 5). Additionally, the EDF formulated demands that exceeded the Commission's initial proposal, some of which have a direct relevance to the research question of cross-border mobility for disabled people: First, the EDF asked to expand the scope of the proposal by including provisions to support disabled who are taking part in EU

Mobility Programmes like Erasmus+ and thus, move abroad for a period of time. Second (and even more significant in context of this thesis' topic), the EDF pointed out the need to have temporary access to social security, social assistance and allowances when a person moves abroad and is undergoing the "reassessment" process for recognition of their disabilities. While, according to expert 5, the second demand has proven to be a red line for the member states, the first demand eventually became EU law.

Three conclusions can be drawn from this example: First, it shows that the organizations representing disabled people have direct access to the European Commission as well as to the European Parliament. Second, it shows that these exchanges with policymakers are at least partially successful. It is therefore not surprising that the disability lobby organizations generally speak positively about working together with the European Parliament. Following the mentioned meeting, the EDF's vice president stated that "*the European Parliament has always been our ally on advancing disability rights, and our meeting with MEP Nicholsonová reassures us that this will be the case for the European Disability Card.*" (EDF Vice-President Gunta Anca, 2023). Finally, the example also shows that the issue of this thesis, which is the systematic disadvantage of disabled people to move and reside abroad, is not only a theoretical problem, but is actively discussed between policy officers representing disabled people and EU policymakers.

That said, it should also be mentioned that although disabled people are well represented by lobby organizations, they are underrepresented by those who are elected to represent the European society – the European Parliament itself. In the current legislative period, only 6 out of 705 MEPs (approx. 0,85 %) have a disability status. That is not even close to the share of people that have a recognized disability status in the EU, which is about 10 %. When asked for reasons for this misrepresentation in the EU Parliament, MEP Katrin Langensiepen (expert 3), who has a visible impairment herself, pointed out two factors of accessibility⁷⁰: First, many polling stations in Europe are not accessible for disabled people, preventing many from casting their vote.

⁷⁰ To read more on the factors of accessibility see **Fehler! Verweisquelle konnte nicht gefunden werden.**

Secondly, information is often not accessible. This is particularly problematic for people with intellectual impairments and is an undeniable example of how discrimination against disabled people affects their rights as EU citizens.

The third and final way of formally influencing policymakers is the Council, thus the representatives of the EU member states (see e.g. Coen, 2007). Unlike the other EU institutions, there is no similar group other than the disability platform at which representatives of the member states are present. The interviewed policymakers from EDF and ENIL (experts 7 and 10) confirmed that the Council is the most difficult to access. The organizations would have to formally request an exchange on a particular issue at the permanent representation of a member state. However, as it was reported, the request would often be unanswered.

This brings us to the informal way of accessing policymakers. All interviewed experts from lobby organisations reported that conversations with national delegations are most successful whenever there is a personal connection. In one example, it was reported that an official from the French delegation had his child in the same kindergarten group as the EDF lobbyist.

There are, however, more informal ways to exchange information, most notably through the two consultative bodies that complement the formal EU institutions: The European Economic and Social Committee (EESC) and the Committee of the Regions (CoR). Especially the EESC often organizes conferences that enable the mentioned stakeholders to directly engage with representatives from the Directorate-Generals, Members of Parliament, and representatives from the member states. Additionally, the two Committees advise the Commission, so they are consulted in all drafts concerning disability-related policies. While neither the EESC nor the CoR have formal legislative power and could formally be ignored by the EU Parliament and the Council, their opinions and statements are highly important in practice. For example, during the interviews with policymakers (experts 1, 3, 4, and 5), the EESC's opinion on the European Disability Rights Agenda and the European Disability Card repeatedly served as a reference point for further discussion.

When analysing the published statements by the two Committees, it can be observed that especially the EESC often demands more rights for disabled

people than the Commission's proposals contain. Still, in their formulation, the rapporteurs are careful to maintain an advisory rather than an activist character. The Committee's statements are not to be underestimated when disability-related issues are being drafted. For that sake, the EESC's Section for Employment, Social Affairs and Citizenship (SOC) established a permanent Group on disability rights. One member of this group has been interviewed⁷¹ (expert 6). She confirmed that sometimes it was notable that the EESC had no formal power, however, at the same time she stressed that the Committee's words are being heard by EU policymakers. Thus, she interpreted her role partially as a "*voice of disability organizations to the EU institutions*" (expert 6).

The close connection between the disability stakeholders and the EESC can also be seen in the example of the European Disability Card, an important legislative initiative to ease cross-border mobility.⁷² Referring to a statement from the Commission regarding the potential impact of this initiative, the EESC published its opinion in the Official Journal of the EU⁷³. The EESC's Rapporteur for this opinion was the representative for the National Confederation of Disabled People of Greece (NCDP), Ioannis Vardakastanis. At the same time, he is also the president of the European Disability Forum (EDF).

Disability groups operate in some ways between business-oriented lobby groups and traditional social interest groups formed to achieve some form of collective good. Many regulations and systems in place that concern disabled people are built on assumptions and prejudices about their health status, their abilities, and their mental capacities. A significant part of disability lobbyism thus consists of changing the perception of disabled people. For that sake, many disability groups are organised in various umbrella organizations in Brussels, most importantly the European Disability Forum (EDF). The leading umbrella organization of service providers for disabled people is the European Association of Service Providers for Persons with Disabilities (EASPD). While being active in European disability policy, the two sides do not necessarily represent the same position.

⁷¹ Ms. Sif Holst, who is also Vice-Chair of the Disabled People's Organisation Denmark (DPOD)

⁷² See chapter 2.3.3

⁷³ Official Journal of the European Union, June 29th, 2023, [\(2023/C 228/09\)](#)

1.3 Citizens' rights in the European policy agenda on disability

To analyse the regulations concerning the freedom of movement for disabled people, it is important first to look at the policy framework in which they are embedded. This approach follows the question of how European decision-makers perceive the issue of citizens' rights and freedom of movement. The key issue to be analysed is whether freedom of movement for disabled people is directly targeted or whether the EU institutions' focus lies elsewhere. In broader terms, it is legitimate to ask whether legislators and officials are at all aware of the problem and, if they are, whether it has been put on the political agenda in the past.

Therefore, after a short introduction about the early developments of European disability policy, the subsequent section offers a discourse analysis of two key documents that have framed European disability legislation in the past two decades. Those are the European Action plan for disabled people 2004-2010⁷⁴ and the European Disability Strategy 2010 – 2020⁷⁵. It is worth mentioning that neither is a legally binding document, but comparably short communication papers by the European Commission that aim to inform about the political agenda in upcoming years. The development has reached its preliminary peak in the European Disability Rights Agenda 2020-2030, whose achievements and shortcomings are still to be determined.

In addition to the targeted disability policy frameworks, at least two other documents must be considered when analysing the place value of citizens' rights in European disability policies: the European Charter of Fundamental Rights and the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The European Commission has repeatedly used both documents as reference points when drafting legislation.

⁷⁴ COM (2003) 650 of October 30th, 2003

⁷⁵ COM (2010) 636 of November 15th, 2010

Year	Policy Framework	Development regarding freedom of movement
1992	Maastricht Treaty	Founding of the EU and European Citizenship
1993-1999	3 rd disability action program (HELIOS III)	Stipulating a policy debate on disability, coordinating the exchange of information.
1999	Treaty of Amsterdam	European Commission gains competence to make legislative proposals to fight discrimination on the grounds of disability.
2000	Charter of Fundamental Rights	The EU recognizes that disabled people have a right to receive disability-related benefits.
2004-2010	European Action plan in Disability	Mainstreaming of disability-related issues in all EU policies, recognizing problems related to intra-EU mobility.
2008 (2010)	UN Convention on the Rights of Disabled people	The EU and all its member states ratified the UNCRPD, which recognizes the right to freedom of movement and links the issue to nationality. The document addresses problems in immigration proceedings.
2010-2020	European Disability Strategy	The EU recognizes that disabled people are deprived of their right of freedom of movement, describing the loss of national benefits as an "obstacle" to exercising European citizenship.
2021-2030	European Disability Rights Agenda	Announcement to work towards the consolidation of social systems, the recognition of disability status abroad, and the right to receive disability-related benefits.

Figure 14: Overview: Milestones framing European Disability

1.3.1 Early Developments: From 'charity' to fundamental rights

When questioning equal rights for disabled people regarding their European Citizenship, the Treaty of Maastricht in 1992, which established these rights, may be a starting point for analysis. In this context, a remarkable milestone has been the third disability action programme (HELIOS III), which was implemented between 1993 and 1996. While the programme prioritised the exchange of information between the member states and national NGOs, for the first time, the focus was laid on the integration of disabled people and the promotion of equal opportunities. However, during this period, the EU's role remained strongly limited to a coordinative role, partly because the disability action programme depicted a purely medical model of disability, while the integration of the health sector itself was still in its infancy.⁷⁶ Instead, efforts by the European Commission were *"still focused on stimulating a policy debate rather than on laying down concrete actions on disability"* (Broderick, 2019, p. 300).

Waddington (2020) points out that a breakthrough in European disability policies was achieved in 1999 with the Treaty of Amsterdam's Article 13, establishing the European Community⁷⁷. This article has *"conferred competence on the EG (now the EU) to combat disability discrimination"* (Waddington, 2020, p. 19). Indeed, in signing the Treaty, the European Commission was granted the mandate to develop policy proposals to combat discrimination, including discrimination against disabled people. Thus, for the first time, it was acknowledged that discrimination on the grounds of disability was a European issue, despite its correlation with social policies (see e.g. Waldschmidt, 2019).

However, in respect to this chapter's focus on policy frameworks, in which policies concerning the freedom of movement of disabled people in the EU are embedded, is also important to point out that at that time, neither has European Citizenship for disabled people been identified as being subject to discrimination nor were the member states willing to give up their final say in anti-

⁷⁶ The Directive 2011/24/EU on the application of patients' rights in cross-border healthcare has been adopted 15 years after HELIOS III.

⁷⁷ Now Art. 19 TFEU

discrimination law. Instead of the ordinary legislative procedure, the Treaty of Amsterdam stated that the Council may only take the anti-discriminatory measures proposed by the Commission “unanimously and within the limits of the powers conferred by it upon the Community” (Art. 13). Nevertheless, at the same time, at the end of the last millennium, the legal competence largely remained within the member states, the discourse on discrimination against disabled people was lifted to a European level.

Another thought regarding the anti-discriminatory approach is related to the different disability concepts. When considering disability as a medical condition, it is desirable to expect prohibiting discrimination on that ground. According to the social model, however, disability is only the result of some form of discrimination based on a personal impairment, which, as previously described in Chapter 1.3, may even be inevitable. Therefore, the ‘prohibition on grounds of disability’ would, by definition, be impossible.

Charter of Fundamental Rights

The Charter of Fundamental Rights (CFR)⁷⁸ was initially drafted in the run-up to the European Council Conference in Nice in 2000 as part of the Treaty establishing a Constitution of Europe. However, after the Treaty failed due to the objections through referendums in France and the Netherlands, it took almost a decade to enter into force. By the time this thesis was written, it had been signed and ratified by all member states except for Poland. For this chapter’s narrative analysis, it is more coherent to see the Charter’s wording in the context of the time it was drafted, rather than its legal effect.

With this in mind, it is remarkable that out of six areas of fundamental rights within the CFR, three concern citizens’ rights, equality, non-discrimination and solidarity.⁷⁹ The provisions on citizens’ rights are essentially a renewal of previous treaties: “*Every citizen of the Union has the right to move and reside freely within the territory of the member states*” (CFR, Art. 45). While the wording ‘every citizen’ generally includes those whose impairments cause a

⁷⁸ Charter of Fundamental Rights (2012/C 326/02)

⁷⁹ The other three areas concern dignity, freedoms, and justice. Additionally, Title VII gives general provisions on the interpretation and application of the Charter.

dependency on social assistance and social services, the wording becomes significant in connotation with the Charter's provisions on prohibiting discrimination, inter alia on grounds of disability or grounds of nationality (CFR Art. 21.1/2).

On the one hand, it is noticeable that neither is discrimination linked to freedom of movement, nor are disability and nationality considered to be possible simultaneous causes for discrimination. However, it is worth pointing out that the CFR also does not explicitly limit the scope of its application other than emphasising that it does not transfer any new power to the EU (CFR Art. 51). Nevertheless, the most remarkable remark within the CFR is the following:

“The Union recognizes and respects the rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community” (CFR Art. 26).

Not only does this statement in the Charter link disability-related benefits to their participation in the (European) community, but it also formulates that disabled persons have a right to receive these benefits. This represents a substantial step since the Charter was drafted only one year after the Commission was given the power to make anti-discriminatory legislative proposals.

Because of a missing legal basis, the wording on how these benefits were to be financed has been drafted much more carefully. Within the area of solidarity, the CFR contains articles on social security and social assistance. It states that the Union *“recognises and respects the entitlement to social security benefits and social services providing protection, in accordance with the rules laid down by the Union law and national law and practices.”* (CFR Art. 34.1).

How is the Charter of Fundamental Rights to be interpreted regarding the question of how European decision-makers view the issue of freedom of movement and citizens' rights for disabled people? On the one hand, in separating citizens' rights from the fundamental rights of non-discrimination and solidarity, the document illustrates the underlying problem that guides this thesis. However, the Charter may also be interpreted differently: While the EU

recognized the right to receive disability-related benefits for the first time, it directly links those benefits to the ability to participate in society. Therefore, despite not (yet) having a strong legal effect regarding the freedom of movement for disabled people, it shows a clear development in how the EU views disability, namely from a charity-based to a human rights perspective.

1.3.2 The 'mainstreaming' of disability interests

Parallel to the fundamental development of establishing a European Constitution (which famously failed in 2005), another significant development regarding the EU is its enlargement of 10 Eastern European countries. While this is not directly connected to the research question, it is worth pointing out the 'hot topics' on the political agenda surrounding the developments in disability policies.

Nevertheless, these developments did not hinder the European Commission from progressing its work on disability-related issues, especially in establishing platforms for exchanging and intensifying its work with organizations such as the European Disability Forum (EDF). Moreover, the Commission has raised awareness for disabled people by declaring 2003 the European Year of disabled people. A previously conducted Eurobarometer survey showed that more than a third of all EU citizens (36 %) had heard about this campaign (Eurobarometer 54.2, 2001). Although there have been significant differences between the member states, this level of raising awareness can be regarded as very successful, especially considering the amount of attention simultaneously given to the enlargement process and the attempts to establish a European constitution.

A case study analysis by Sturm et. al. (2017) emphasized the importance of 'political opportunity structures' for disability lobbying to be successful. In a way, the European Commission has created a window of opportunity to put disability policies on the agenda, resulting in the first European Action Plan on Disability in 2004. The aspiration that was granted to this document was not less than being a "*reference point and framework for reinforcement of the disability dimension in all relevant EU policies, while supporting or stipulating policies at the national level*" (COM (2003) 650, p. 3). Within the Action plan, this has been

described as the '*mainstreaming*' of disability policies, marking the first of three operational objectives.⁸⁰ In that context, the following paragraph within the European Action plan has been remarkable:

“Supporting citizens with disabilities to become an effective part of the economy and society as a whole means participation in the mainstream [...] rather than segregation into disability-specific arrangements.” (COM (2003) 650, p. 6).

This wording shows that instead of seeing disability issues as an outskirts area of social policies (in which the EU has no say), the Commission regards disability as a layer that must be considered when drafting policies on all kinds of issues. Furthermore, it shows that the Commission did not intend to 'push' member states towards taking specific steps or even to work towards an EU mandate over disability policies, but rather to bring about changes through *including* disability-related issues in existing European policy fields. With the increasing popularity of the social model of disability, this approach of mainstreaming disability has gained high significance in disability studies (E.g. Albert, 2006; Schur a.o al., 2013). While the debate exceeds the scope of this paper, on the EU level the approach has been proven to be at least partially successful since 2004. For example, mainstreaming the health care sector has led to further integration in this field, significantly impacting the treatment of senior citizens.

Recognizing the limits of its mandate in social policies, however, the Commission stresses that *“employment remains the most critical factor for social inclusion”* (ibid.). This intense focus on the employability of disabled people is reflected in the four proposed action fields that marked the framework for disability policy until 2010.

- Access to employment (including the fight against discrimination)
- Lifelong learning and personal development to promote employability and active citizenship
- Development of new technologies to empower disabled people and therefore facilitate access to employment

⁸⁰ The other two objectives have been achieving equal treatment in the Employment and Occupation Directive (2000/78/EC) and improving accessibility

- Improve participation in the workplace and integration into the economy and society through access to the public built environment.

By emphasising concepts such as empowerment, improving accessibility to employment, and personal development, the action fields put the responsibility on the individual level. The Commission defined its role in “*support[ing] efforts to make the strategic business case of disability recognised more widely*” (COM (2003) 650, p. 5). Remarkably, this left those unable to participate in the mainstream labour market out of sight. Considering the Eastern enlargement of 2004, it is likely that the topic of social security was too sensitive to be included in the action plan.

Considering general public apprehensions (or at least their assumption among policymakers) of so-called ‘social tourism’ (e.g. Tryfonidou, 2013; Vonk, 2020) from the new member states, it is unsurprising that the freedom of movement of disabled people has not yet been included in the action plan’s focal points. Instead, because little was known about the situation and needs of disabled people in the new member states, studying their situation has become a key focus for developing future disability strategies (ibid., p. 9).

However, by dedicating a short paragraph to the issue, the European Commission did acknowledge that freedom of movement is limited for disabled people. The Commission’s reluctance to tackle the issue of freedom of movement and citizens’ rights becomes visible by the sheer shortness of the respective paragraph. Despite naming freedom of movement “*one of the founding freedoms of the Treaty*” (COM (2003) 636, p. 9), the words regarding the exportability of benefits had been chosen extra cautiously:

“The Commission has already committed itself to reviewing the current exemption of disability benefits from the exportability provisions of Regulation EEC 1408/71 with a view to reducing the number of such benefits that are currently not exportable” (ibid.)⁸¹

⁸¹ For an analysis of Regulation 1408/71 on the application of social security schemes to employed persons and their families moving within the Community see chapter **Fehler! Verweisquelle konnte nicht gefunden werden.**

The paragraph shows a degree of problem awareness and the Commission's intention to work on it, while simultaneously demonstrating how the Commission's possibilities are limited to "*having a view.*" One primary legislative tool to be applied was to include measures in the European Social Fund (ESF) that would foster the inclusion of disabled people in the labour market⁸².

To sum up, regarding how disability, in general, was embedded in EU policies, this is the answer: The action plan's focus was to integrate disabled people in the labour market to increase the workforce and decrease welfare costs. While the action plan did not include any provisions regarding freedom of movement, the Commission had shown its awareness of the problem.

Additionally, one can observe changes on a more abstract level in how the EU views disability. For example, in the context of the elimination of barriers the communication paper reads "*the EU also sees disability as a social construct*" (COM (2003) 650, p. 4) and "*environmental barriers in society [...] prevent the full participation of people with disability in society*" (ibid.). Thus, congruent with the Charter of Fundamental Rights, which showed a development towards a human rights perspective, the European action plan recognised the social element of disability for the first time.

1.3.3 The growing significance of freedom of movement

When analysing the framework for EU disability policies, one cannot ignore the developments on an even greater scale, namely the signing of the UN Convention on the Rights of Persons with Disabilities in 2006. Not only is the UNCRPD the one document that has had the most significant impact on the lives of disabled people after it entered into force in 2008, but it has also been signed by all 27 EU countries *and* the EU as a supranational organisation. The Council signed the UNCRPD in 2009, entering into force in January 2010 (Council Decision 2010/48 EC). The latter is particularly remarkable because, for the first time, a regional organisation became a party to an international human rights treaty.

⁸² Within the ESF the EU established the so-called EQUAL programme which included the increase of employability of disadvantaged groups as one of five pillars. The EU contributed 3.274 billion Euros to EQUAL, an even amount was contributed by the member states.

Regarding the question of this section, how legislation concerning the freedom of movement of disabled people is framed, the UNCRPD's wording is essential. Even more so, since the issue is addressed directly:

“States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities (a) have the right to acquire and change a nationality, [...] (b) are not deprived, on the basis of disability, of their ability to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement and are free to leave any country, including their own.”
(UNCRPD, Art. 18)

On the one hand, the UNCRPD is remarkably specific in not only dedicating a whole article to liberty of movement as a right but also in pointing out potential problems such as equal access to immigration proceedings. On the other hand, it is remarkable that for the first time, the problem of freedom of movement is directly linked to the person's nationality, going as far as to point out that the right includes a right to *choose* where she/he wants to reside and even a right to change the nationality.

However, it would be wrong to simply derive a European regulation from this wording. For one, even though the EU has signed the UNCRPD, the article commits *states* parties. Because the EU itself is not a state, it can be argued that the EU has committed itself to a right that it has no competence to grant. Additionally, even though the state parties (including all EU member states) confirmed the citizens' right to leave the country if they wanted, the UNCRPD does not commit the receiving countries to take the necessary measures to include that person in their society.

Therefore, while the wording of the UNCRPD shows progress, it is important to keep in mind that it has not been written in the context of European law, but the EU and its member states have committed themselves to its implementation. For that reason, the question remains whether the ratification of the UNCRPD is primarily symbolic or whether it had a significant impact on persons with disabilities. Because this topic contains enough substance for an intense debate

on its own, Uldry (2016) has addressed this question from a legal point of view. Her conclusion is to some extent twofold: On the one hand, she observed “a positive influence in the EU as it exceeded the sole protection of the internal market” (Uldry, 2016, p. 36), on the other hand, she concedes that “persons with disabilities still lack access to judicial remedy when the Union or its member states acting within the scope of EU law fail to comply with the CRPD.” (ibid).

This is a significant finding in the context of the development of the European framework for disability policy: While the European Action plan aimed at mainstreaming policies to include disabled people in the workforce, the UNCRPD has initiated a shift from a purely economic perspective towards a rights-based approach.

The European Disability Strategy 2010

With the European action plan on disability phasing out, the European Commission drew up a succeeding framework, namely the European Disability Strategy (EDS) 2010 – 2020. It is worth noting that the scope of this framework includes not only the objectives for implementing European disability policy but also the implementation of the UNCRPD at the EU level and the support of the EU member states in implementing the Convention at the national level⁸³.

Again, just like the previous Action plan, the EDS is not to be understood as a set of rules and regulations, but rather a statement by the European Commission of what would be on the political agenda. The superordinated aim of this strategy was to “empower disabled people so that they can enjoy their full rights and benefit fully from participating in society [...]” (EDS, p. 4) that was to be achieved through regulation in eight priority areas, each affecting the intra-EU mobility of disabled people in some way.⁸⁴ However, having set such a general goal, the length of the entire EDS document did not exceed eleven

⁸³ See *Description of the European Disability Strategy on the European Commission’s website (DG EMPL)*, retrieved February 23rd, 2021

⁸⁴ Accessibility of goods and services, Participation and removal of barriers, equality and anti-discrimination, employment in the open labour market, education and training, social protection, health and promoting the rights of disabled people in the EU enlargement and international development programmes.

pages. It might be due to this shortness that the wording concerning the freedom of movement for disabled people is remarkably clear:

“There are still many obstacles preventing disabled people from fully exercising their fundamental rights - including their Union citizenship rights - and limiting their participation in society on an equal basis with others. Those rights include the right to free movement, to choose where and how to live [...]” (EDS, p. 5).

In this sentence, the EU Commission has stated for the first time that the potential difficulties which disabled people may face when going abroad constitute a deprivation of their rights as European citizens. Thus, the EU has adopted the UNCRPD's acceptance of a rights-based approach. This step is not to be underestimated, because it is no less than the admonishment of discrimination against disabled people, which the EU has previously been given the mandate to address. The explanation for why the Commission addressed the issue in such an unambiguous way has been given in a Staff Working Document that accompanied the EDS⁸⁵:

“Evidence suggests that the majority of disabled people do not take advantage of their right to free movement and that they know little about the European initiatives in place to support free movement. Around 60% of respondents to the public consultation for the Disability Strategy 2010-2020 agreed or strongly agreed that the strategy should address the fact that EU citizens with disabilities find it more difficult to move to another Member State than other EU citizens” (European Commission Staff Working Document, 2010, p. 25).

On basis of the public consultation in the run-up to the EDS, the European Commission took its chance to open the door to make legislative proposals regarding freedom of movement for disabled people on grounds of anti-discrimination.

To underline this ambition, the EDS went further by stating that *“the Commission will work to overcome the obstacles to exercising their rights as individuals [...] and tackle the problems related to intra-EU mobility” (EDS, p. 5).* The European Commission specified these obstacles by exemplifying that “a

⁸⁵ SEC(2010) 1323 final

person with a recognised disability moving to another EU country can lose access to national benefits" (ibid.). In the context of this narrative analysis, it is astonishing that the Commission described the loss of national benefits as an '*obstacle*' (which needs to be overcome). Not only does this show a strong awareness of the problem by the Commission, but also its willingness to actively work towards further integration in this area, despite its entanglement with the national disability regulations and social security systems of the member states.

In order not to overestimate this thought, however, it should also be pointed out that the national benefits that were instanced were neither assistance services nor social entitlements for housing, but free public transport and access to public institutions such as museums. Instead, these issues are dealt with under a separate headline concerning social protection. Acknowledging the legal boundaries, the Commission defined its role in "*support[ing] national measures to ensure the quality and sustainability of social protection systems for disabled people, notably through policy exchange and mutual learning.*" (European Commission Staff Working Document, 2010, p.8).

Regarding the overarching objective of analysing how the pre-political framework has been shaped regarding problem-awareness, the European Disability Strategy has been a major development from the European Action Plan, in which the right of freedom of movement had played no role. Not only did the public consultation preceding the EDS illustrate the problem, but the Commission even went as far as to qualify the loss of national benefits as "*an obstacle to exercising citizens' rights*" (ibid.).

Since the EU has no legal basis to directly regulate government benefits for disabled people, the EDS did not include any provisions in this direction. However, the Commission has already used its research funds to identify concrete challenges that disabled people face when moving abroad through a study carried out by the University of Valencia. This may very well be interpreted as the European Commission's intention to find European solutions to this problem.

1.3.4 The political agenda until 2030: Consolidating disability benefits

In March 2021, the European Commission released its long-awaited political framework for its disability policies until 2030, formally known as the Strategy for the Rights of Persons with Disabilities (SRPD) 2021-2030.⁸⁶ The new strategy has been delayed due to the COVID-19 pandemic and its severe impacts on disabled people. Especially those living in residential care have been hit by higher infection rates while at the same time suffering from social distancing rules. Due to the strong efforts by lobby groups, measures that specifically aim at counteracting these negative impacts were to be included in the Strategy. Despite the urgent need for immediate action regarding COVID-19, the Commission cemented its previously started rights-based approach to disability in naming the new policy framework a disability *rights* agenda.

Concerning the Commission's problem-awareness regarding the research question, the SRPD has lifted the topics of European citizens' rights and freedom of movement to another level. As in its previous strategies, the European Commission has formulated key areas where it plans to develop policy proposals. The SRPD, however, dedicates one solely to disabled people's ability to enjoy their EU citizens' rights, explicitly the ability to move and reside freely within the EU. Herein, the Commission recognizes that when moving abroad, "*persons with disabilities may experience difficulties in having their disability status recognized. This means that they may face barriers to access services, including (...) benefits for persons with disabilities in that country.*" (SRPD, p. 9).

In pointing out the recognition of the disability status and the access to disability-related benefits as key obstacles to moving abroad, the Commission has finally named the sore point. As outlined in chapter 1.1, the definition of disability and the determination of individual needs are far from homogeneous among the member states. Likewise, the organization of disability-related benefits, which derives from the status recognition, is in most cases at least partially entangled with the respective social security system. Given the

⁸⁶ COM (2021)101 Communication from the European Commission. March 3rd, 2021. *Union of Equality. Strategy for the Rights of Persons with Disabilities 2021-2030.*

Commission's limited competence in this field, it is remarkable that the mutual recognition of disability in all member states and the provision of services related to this status are supposed to be at the centre of the European Commission's actions and policy proposals.

Additionally, for the first time, the Commission went beyond pointing out the problem regarding free movement by announcing a flagship initiative to achieve equal opportunities for disabled people to move freely. Building on a previous Pilot Project, the Commission announced its intention to propose a 'European Disability Card' by the end of 2023, requiring unanimous approval by all member states to become law. If adopted by the member states, this Disability Card was set to constitute a European regulation regarding status recognition, a core area of disability policy.⁸⁷

While this unambiguous attempt to harmonize national disability policies is already a significant development, it is followed by provisions regarding the 'consolidation of social protection systems' (SRDP, chapter 4.4, p. 15), which are no less progressive. The Commission points out that "*member states have intensified reforms of their social protection systems including of their disability assessment frameworks and benefits*" (ibid.), adding that "*a considerable number of member states have received support for reforms of their social protection systems from the Commission through the Structural Reform Support Programme*" (ibid.). Thus, although the European Commission has no mandate to harmonise the national social protection systems, its financial tools foster their consolidation.⁸⁸

To set the basis for consolidating social systems, the European Commission aims to reduce the differences between the member states regarding disabled people's social protection. For that sake, the Commission announced a study on social protection and services for persons with disabilities to be launched in 2022 and calls on the member states to "*tackle gaps in social protection for disabled people to reduce inequalities, including by compensating extra costs related to disability and eligibility for disability benefits*" (SRPD, p. 16). Although

⁸⁷ The European Disability Card is analysed in the upcoming chapter 2.3.3

⁸⁸ Between 2021 and 2027 the member states can apply for funding for reforming their social security systems under the Technical Support Instrument (TSI).

this sentence is arguably 'only' a call on the member states, the wording goes far beyond the previous EDS until 2020, moving the Commission to the edge of its competencies. Thus, next to the problems concerning the recognition of disability status, the Commission directly addressed problems related to national disability benefits and social security. While the consolidation of social systems already occurs in other areas, disability funds have been carefully excluded⁸⁹. To sum up, by 2021, the topic of citizens' rights and freedom of movement for disabled people has not only been recognized and put on the political agenda but has even gained high priority.

Despite this far-reaching wording, it remains questionable to what extent the proposed actions can reach beyond a memorandum and have an impact on disabled people's ability to exercise their rights, given the competence struggle in which the Commission finds itself. For that sake, the EDF has analysed and quantified the different tools that are proposed to implement the SRPD, visualizing as such:

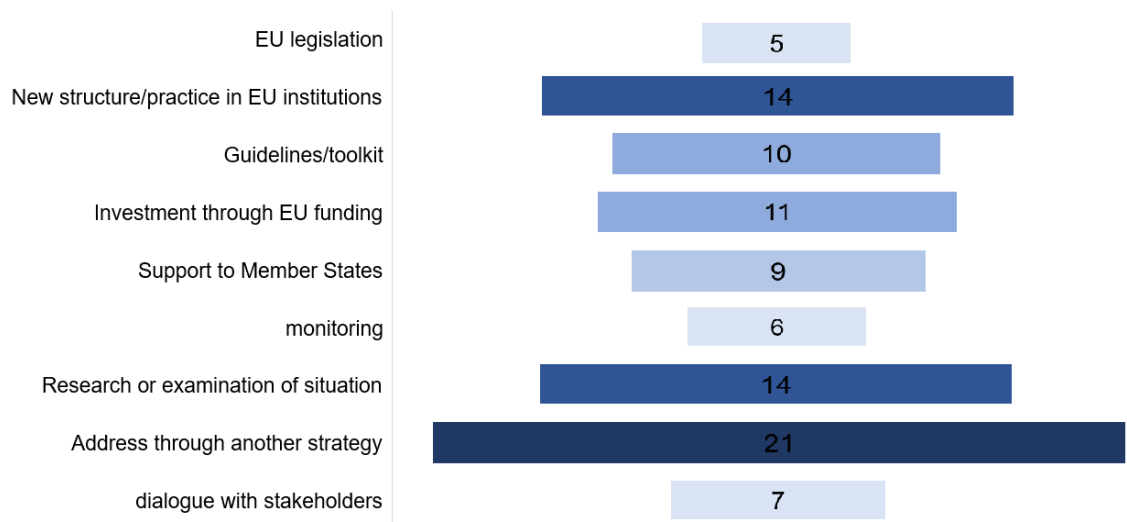


Figure 15: Number of Actions by Type in the European Disability Rights Agenda 2021-2030

It becomes clear that only five initiatives announced in 2021 had a legally binding character, while the majority of 92 actions are much vaguer.

⁸⁹ The coordination of social security systems is subject to the analysis in chapter 2.2.1

When the EDF presented these results at a conference⁹⁰, the author of this thesis asked the representative of the EU Commission, who heads the Disability and Inclusion Unit (Expert 1), how she would rate the SRPD. The question focused on her assessment of the extent to which the SRPD will be more than lip service and whether it can lead to real change. Her response was remarkable: „*We do not know yet which legal basis we are going to use to make the Member States comply with the SRPD, but we will find one*”. (Expert 1, 2021).

Freedom of movement for disabled people remains entangled with the national disability benefits and social security systems, which the EU has no competence to regulate. However, the narrative analysis of key documents framing the EU's approach to disability since the turn of the millennium shows an increasing awareness of the problem by the European Commission. The recognition of potential deprivation of citizens' rights through the loss of national benefits points out a tendency towards a stronger European involvement. In 2021 the issue has gained momentum in the European Disability Rights Agenda, in which the European Commission announced its intention to bring forward a policy proposal on the exportability of disability-related benefits.

⁹⁰ Source: Presentation by the European Disability Forum, March 17th, 2021

Research Layout	Part I: Meta- or pre-political factors	Part II: Factors related to institutional or policy design	Part III: Factors related to the implementation of the relevant policy
Research Topic	Representation and political lobby of disabled people in EU policymaking	Subcategories of disability-related policy <ul style="list-style-type: none"> • Self-determination / non-discrimination • Social security / Cash transfer • Autonomy / Personal assistance 	Euregio Meuse-Rhine (DE, NL, BE) as best-case examples for cross-border coordination in economic, cultural and social matters.
Guiding Question	Is cross-border mobility of disabled people a real problem and have disabled people the means to bring this topic on the political agenda?	Does the subsidiarity principle contradict citizens' rights at the expense of disabled people and are there attempts to challenge the ESM's status quo?	Does intensified coordination enable disabled people to exercise their rights as European Citizens?
Independent Variable	Representation of disabled people on EU level and their access to EU policymakers	EU policy fields: <ul style="list-style-type: none"> • Anti-discrimination and equal treatment • Coordination of social systems • Accessibility to social services (SSGI) 	Coordination between local actors (public authorities, service providers)
Dependent Variable	Problem-awareness by EU policymakers and disability-related policy agenda	<i>De jure</i> ability of persons with disability to move and reside abroad	<i>De facto</i> ability of persons with disabilities to move abroad
Analytical Tool	Analysis of Disability Lobby and its impact on EU Disability Strategies; Expert interviews with key stakeholders	Analysis of legislative acts and stakeholder's opinions; Expert interviews with EU officials, elected MEPs and EESC members, Council representatives	Quantitative analysis of affected people, qualitative analysis of disability systems within the EMR; Expert interviews with local officials and service providers.
Relevance to Research Question	Is the research topic regarded as relevant? Who is challenging the ESM's status quo regarding disability?	How is the issue of freedom of movement affected by disability-related EU policies and where is it challenged?	How do European policies affect Active European Citizenship of disabled people in practice?

Figure 16: Part II: Summary Methodological Research Layout

Part II: The design and development of EU disability policy

“Disability does not represent an exception to the general pattern of anachronistic and uncoordinated programs that are resistant to change. In disability, as in social welfare in general, the only avenue to fundamental reform is to add another program to existing programs and to cope with the resulting confusion.” (Edward D. Berkowitz, 1987)

2.1 The influence dimension: Self-determination vs. discrimination

The first area to be analysed regarding the possibilities of disabled people to exercise the right to move and reside freely within the EU is whether the public is actively enabling them to do so. This relates to the ‘influence dimension’ defined by the DISCIT researchers⁹¹. It asks whether public policy, by a mix of regulatory and retributive measures, enables disabled people to define their own needs and make their own decisions, including the decision to move within the EU. While the retributive measures in the upcoming chapters are being addressed regarding access to SSGI to compensate for an otherwise inaccessible environment, this chapter addresses the regulatory aspect regarding the influence of disabled people.

In this context, a ‘regulation’ does not necessarily need to be enshrined in legislative acts but is instead primarily understood as a set of moral standards and behavioural rules regarding disability. Hvinden has defined this as a “*social regulation system*” (Hvinden, 2017) that is potentially followed by ECJ judgments as well as legislative acts in accordance with this system. Likewise, this ‘social regulation system’ is not to be mistaken for the previously addressed ESM.

This social regulation system is built on *assumed* characteristics or limitations of disabled people. For instance, when consulting friends or colleagues in the drafting phase for this thesis, a common concern has been whether disabled

⁹¹ See “The Three Levels of Active European Citizenship”

people would have the mental capabilities to move abroad and adapt to a changing cultural environment. Some remarks even went beyond that by questioning whether disabled people could even have that wish, suggesting that those who need assistance in their daily lives would likely not be able to judge the consequences of their decision to live abroad. This might hold for some, if not many, disabled (and non-disabled) people. However, it surely does not apply to all, but this 'regulating social system' is based on the common assumption that disabled people in general would not want to go abroad. According to the interviewed EDF expert, this is partly because European integration in general is an 'elite project' of men and women with a solid financial background. Most of the time, disabled people are not associated with that group (expert 7).

The assumptions that form social systems not only relate to what disabled people cannot do, but they also result in expectations of what disabled people can and should do, sometimes even assigning them some sort of 'super-power'. For instance, a well-known German Newspaper⁹² reported on an IT company that allegedly made the diagnosis of Autism a mandatory criterion for hiring employees, because "*they work exceptionally focused and with high quality-awareness*" (Aldenhoff, 2019). Similar patterns can be observed towards people with some form of physical impairment. For instance, the assumption that all blind people can hear exceptionally well compared to non-blind people, or in the field of disability sports, where disabled people are often expected to perform exceptionally well in an 'unusual' way.

This is, of course, a two-edged sword: On the one hand, examples like these illustrate the numerous possibilities of including disabled people in the so-called first labour market. On the other hand, it fosters a lack of understanding for every Autistic person who continues to struggle on the labour market, without acknowledging the individual's impairments. The best-case examples of well-performing disabled people foster the idea that 'there are ways', potentially leading to the conclusion that there is no need for society to include disabled people better. Additionally, whether that person wishes to work in this field may

⁹² Süddeutsche Zeitung, December 29th, 2019

appear less relevant (although not every Autistic person wishes to become an IT specialist).

One aspect these (non-legal) social systems have in common is that they are, at least to a great extent, based on biases and stereotypes. It is for that reason that disability lobbyists in Brussels define the breaking up of these stereotypes as one of their key responsibilities (experts 7, 8, and 10).

It is precisely the issue of stereotypes and assumptions about disabled people's capabilities that connects these 'regulatory social systems' to the research topic of disabled people's ability to move freely. The relevance of these issues lies in the concrete, discriminating consequences that these prejudices follow. Numerous examples of discriminatory action follow the prejudice that disabled people cannot reflect on their own decisions and therefore, are to be guided. One prominent, yet inglorious case on the EU level is the far-reaching exclusion of people with intellectual impairments from European elections.⁹³

In the context of discriminatory measures that result from biases towards disabled people, three thoughts need to be considered: First, in a non-academic discourse, the word 'discrimination' has a connotation of an unacceptable circumstance that needs to be changed. Formulations such as the 'principle of non-discrimination' enshrined in the EU Charter of Fundamental Rights⁹⁴ support this connotation. In an academic discourse, however, discrimination is not to be confused with unequal treatment, which, as a society, we are willing to accept for countless purposes. For instance, few people would see a form of discrimination in the exclusion of mentally or psychologically disabled impaired people from achieving a driver's license, if the respective assessment of that person's ability to drive demonstrates a risk to traffic safety. Regarding disabled people's inability to move freely within the EU, it must be distinguished whether it results from discrimination as defined by the ECJ⁹⁵, or a well-justified unequal treatment.

⁹³ According to the EESC, about 800.000 EU citizens from 16 member states are deprived of the right to participate in European elections because of their disabilities or mental health problems. The extent of this phenomenon is very uneven across individual countries. (EESC Information Report SOC/554-EESC-2017-00587, March 20th, 2019).

⁹⁴ Charter of Fundamental Rights, Article 21

⁹⁵ See Figure 16: Approaches to discrimination by the ECJ

Second, even the prohibition of discrimination on grounds of nationality as explicitly named in the Charter (Art. 21, paragraph 2) is not absolute. Instead, unequal treatment of EU citizens with different nationalities may be justified if it is thought to be unavoidable to achieve a purpose of higher value, such as to ensure public order. A prominent example that gained lots of media attention was the exclusion of non-Dutch citizens from coffeeshops in the Dutch border regions in 2010. The ECJ has confirmed that this form of discrimination on grounds of nationality is an effective measure to counter drug tourism and therefore to ensure public order.⁹⁶

Third, like every system, social regulation systems have restricting effects that might discriminate against a certain group. However, most systems have not developed by coincidence, but for specific reasons that may justify these restrictions. Thus, when discussing any discriminatory measures from a sociological point of view, the question is whether the prevailing norms and values in society perceive disabled people as being discriminated against, and whether this has changed over time. Consequently, the focus is not primarily on eliminating discriminatory measures, but rather on determining whether the justification for establishing them in the first place remains valid or outdated. This includes those measures that deprive disabled Europeans of their citizens' rights.

This chapter focuses on discrimination against disabled people and European non-discrimination law. As previously laid out, the central question in this context is not if but why disabled people are still being deprived of their citizens' rights despite the already identified problem awareness and attempts by EU policymakers to change it.

To assess this question, the following paragraph analyses the understanding of 'discrimination' by the EU institutions, particularly the ECJ. The subsequent sections illustrate how this understanding relates to the concept of multiple discrimination and why it is problematic when discrimination occurs on the grounds of disability. Eventually, it is shown that due to very different biases and social norms towards disability, the EU member states have failed to establish joint non-discriminatory measures that would fully ensure equal treatment.

⁹⁶ Case C-137/09 Marc Michel Josemans vs. Burgemeester van Maastricht

2.1.1 Why discrimination on grounds of disability is different

In the early years of anti-discrimination law, the issue of disability has proved to be problematic. While the EU does not have a single legislative act to protect disabled people from discrimination specifically, the issue has been dealt with differently at a national level. Great Britain, which has often been a forerunner in including disabled people, introduced the Disability Discrimination Act (DDA) in 1995. However, while being exceptional then, the DDA has faced intense criticism. *“In practice, the tribunals adopted a particularly narrow approach to defining disability. To claim protection under the DDA, claimants had to establish that they were “disabled” by demonstrating a physical or mental impairment that had a substantial and long-term adverse effect on their abilities to carry out normal day-to-day activities”* (Vanhala, 2011, p. 212). In many cases, this has been a humiliating request, especially for those whose impairments were not visible at first sight. This humiliation that comes along with demonstrating one's own inability to perform a particular task is the first difference of disability compared to other protected grounds, such as gender.⁹⁷ In most cases, a discriminated woman does not need to demonstrate that she is indeed female, nor does she need to explain that she is giving birth and not her husband.⁹⁸ Disabled people, on the contrary, are made responsible to demonstrate that they are in fact ‘different than others’.

Nevertheless, instead of conducting a particular legislative act to combat discrimination on grounds of disability, the EU member states introduced a general article to combat discrimination in the EU Treaties two years after the DDA, which equally named disability among other grounds:

“[...] the Council, acting unanimously on a proposal from the Commission and after consulting the European Parliament, may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.” (Treaty establishing the European Community, Art. 13, 1997)

These words are still the legal basis for all European non-discrimination legislative acts. The wording itself is remarkable, because instead of a non-

⁹⁷ Requirements to prove discrimination based on sexual orientation have led to similar humiliations.

⁹⁸ Athletes in professional women's sports with higher testosterone levels being an exception

specific memorandum to combat discrimination, the article names exclusive characteristics that are to be protected by EU law. In that regard, disability stands on equal footing to the other listed characteristics. The article is also remarkable regarding its content between the lines, meaning which characteristics are *not* included – in particular the missing characteristics of nationality.

Based on Article 13, the Council adopted the EU directive on equal treatment in employment in 2000 to protect the rights of disabled people in the field of employment and training. While in the context of labour, the directive states that *“discrimination based on religion or belief, disability, age or sexual orientation may undermine the achievement of the objectives of the EC Treaty, in particular the attainment of a high level of employment and social protection, raising the standard of living and the quality of life, economic and social cohesion and solidarity, and the free movement of persons”* (Council Directive 2000/78/EC, Art. 11). Thus, the connection between discrimination and ability to move freely is the second difference between disability and grounds such as gender or nationality. However, the obstruction of free movement is seen as a potential consequence of discrimination, not its cause.

A third difference results from the non-coherent models of disability, as explained in chapter 1.1, and the partly opposing approaches of the medical versus the social approach. Bunbury argues that *“these conceptual models are crucial to both the understanding of disability discrimination, and the intention of legislative provisions aimed at combating disability discrimination.”* (Bunbury, 2019, p. 27). He points out that, compared to other sources of inequality, such as gender, sexual orientation, or race, disability has been given significantly less attention when drafting anti-discrimination law. The reason for this is that while other grounds of discrimination have been perceived as ‘different but equal’, the medical approach to disability has perceived disability itself as a problem that needs a solution, not a characteristic that needs protection. Furthermore, if the ‘problem’ cannot be solved, the disabled person is different and not equal, potentially justifying different treatment. This understanding consequently resulted in unequal treatment before EU law.

Now, the question arises whether the increasing significance of the social model of disability would make the previous thought redundant. Interestingly, however, while the medical and social models offer different solutions to the same problem of a disabled person, neither approach accepts the status quo (ibid.). Thus, instead of just combating discriminatory measures, both models follow the goal of combating disability as such. This is key to understanding why disability is still different from other grounds of discrimination.

In the early years of EU anti-discrimination law, the focus on the medical model has led to equivalent attempts to deal with disability, however, accepting to a certain degree that disabled people are different. The increasing significance of the social model, in contrary, results in a rather philosophical question: If disability is to be understood as the loss of opportunities in society caused by society's failure to break down physical and social barriers, is not the very concept of disability best described as a form of discrimination in itself? If *"disability is regarded as a social creation which causes the impairment to be a problem"* (Shakespeare, 2006), what is the added value of the 'prohibition of discrimination on grounds of disability' as enshrined in EU law? When asked this question, the interviewed EDF's policy officer affirmed the description, yet found this view 'impractical' in the communication with the European Commission (expert 7).

Therefore, regarding discrimination against disabled people, the distinction between 'impairment' and 'disability' becomes crucial, and the prohibition of discrimination on grounds of a mental, psychological, or physical impairment would appear to be more expedient to combat discrimination against disabled people.

To sum up, the overwhelming difference between discrimination on grounds of disability compared to other grounds is that disability has been viewed as a problem that needs solving, not a characteristic that needs protection. Instead, disability is either considered a condition that needs to be cured (medical perspective) or a circumstance that needs to be dissolved (social perspective). The consequence of this difference is that the distinction between disability and impairment in EU anti-discrimination legislation is missing, and that disabled people have been given less attention than other disadvantaged groups.

2.1.2 The EU's approach to anti-discrimination

While the member states have unanimously agreed on the principle of non-discrimination within the Charter of Fundamental Rights (Art. 21) and in EU primary law (Treaty of the European Union, Art. 6), they did not include joint definitions of discrimination or equal treatment. Both, however, are quite complex notions that may not only depend on the respective circumstances, but they may also develop over time. For that sake, *“European countries have pursued equality and non-discrimination beyond rule of law principles of citizenship and equality before the law”* (de Vos, 2020, p. 63).

This insufficiency of the principle of non-discrimination by itself becomes visible through the existence of secondary non-discrimination law itself and in case law by the ECJ, which defines the occasionally narrow line between equal treatment and discrimination. The ECJ has repeatedly defined discrimination as the *“application of different rules to comparable situations or the application of the same rule to different situations”* (e.g., case C-486/18, RE vs. Praxair). This is essentially the difference between the formal (or symmetrical) and the substantive (or asymmetrical) approach to discrimination:

Formal/symmetrical approach	Substantive/asymmetrical approach
<ul style="list-style-type: none"> • emphasizes neutrality expressed through equal treatment of comparable situations. • requires comparison with a comparator to ‘prove’ discrimination. • focuses on equality for individuals, formal neutrality, and procedural justice. 	<ul style="list-style-type: none"> • considers collective dimensions such as structural inequality or societal realities. • focuses on group characteristics and (dis)advantages. • emphasizes broader context that affects personal merit, rather than focusing on the individual.
<i>“Different rules apply to the same situations.”</i>	<i>“The same rules apply to different situations.”</i>

Figure 17: Approaches to discrimination by the ECJ⁹⁹

⁹⁹ based on Fredmann (2016) & de Vos (2020)

For apparent reasons, applying different rules to different situations is not included in the ECJ's definition. For example, being at least 18 or underage is a significant difference that justifies different rules for driving. However, regarding disability, whether a situation is different is precisely the narrow line that often needs to be assessed in court: Is being 'disabled' being considered significantly different than being non-disabled (which is the assumed normal), and does this justify different rules?

Furthermore, non-discrimination measures are differentiated in two dimensions: The vertical dimension, in which non-discrimination rules limit or direct the course of political or collective action, and the horizontal dimension, which is defined by non-discrimination rules that restrict the scope of freedom of private actors or companies.

Regarding disabled people's ability to move and reside within the EU, it is primarily the vertical dimension of potential discrimination that is being addressed in this thesis. This thesis's research question also suggests that being disabled (regardless of the social vs. the medical approach) changes the situation. Thus, discrimination occurs because the same rules apply. The Commission's proposals to overcome this discrimination, for instance, with the introduction of a European disability card, are an attempt to establish different rules because the situation for disabled people differs from that of non-disabled people.

As the ECJ's definition illustrates, today's EU anti-discrimination law cannot be placed entirely into either of them. De Vos explains this with the "*expansion of equality and non-discrimination principles through the historical evolution of EU treaties and to its gradual development through case law*" (de Vos, 2020, p. 64). As he points out, the formal approach was predominant initially, while the substantive approach developed decades later. The reason for this development is tied to the EU's nature. Originally, non-discrimination measures arose from ensuring free trade and freedom of movement (Bernard, 1996; Schmidt et.al, 2020). In this regard, "*non-discrimination primarily served economic integration*" (de Vos, 2020, p. 64). However, while the EU has evolved beyond its purely economic nature, its approach to non-discrimination has also evolved, to the point where it is now a citizen's right (Schmidt, 2020).

In contrast to this development, de Vos has analysed that “*the case law of the ECJ, as well as the statutory prohibitions of discrimination in various EU directives, continue to define non-discrimination through a formal lens that derives discrimination from a difference in treatment in comparable situations*” (De Vos, 2020, p. 65). This understanding of non-discrimination by the EU Commission and the ECJ partly answers this chapter’s question of why disabled people are still being discriminated against in their right to free movement. To prove before the court that a disabled person is being discriminated against, he or she would need to demonstrate that another person with comparable needs and similar assistance has been treated differently.

At first glance, this leads to a ‘disability-paradox’ regarding anti-discrimination. On the one hand, when viewing disabled people as a group, the risk of poverty is far higher than that of non-disabled people. Therefore, the same rules apply, although the situation is different. Thus, disabled people are, according to the substantive approach, in fact discriminated against. In that regard, it is worth pointing out that this thesis’s research question is based on the substantive approach to discrimination against disabled people.

On the one hand, however, the modern understanding of disability (social and medical model alike) recognizes that disability is the result of an individual impairment in the context of the individual circumstance (as laid out in chapter 2.1). Thus, according to the formal approach’s focus on the individual, simply acknowledging disability cannot be grounds for discrimination unless every disabled person is being discriminated against.

This paradox can be solved by distinguishing between cause and effect. While the causes for disability are diverse regarding type and scope of the impairment as well as the individual circumstances, they have the same effect of putting the disabled person at greater poverty risk and thus, dependence on social aid. The discrimination, at least according to the substantive approach, results from applying the same rules to disabled and non-disabled people, despite disabled people’s higher poverty risk.

The ECJ’s standpoint on direct vs. indirect discrimination

The previous chapter has shown the distinction between the formal and substantive approach to discrimination and concluded that, in the context of free

movement within the EU, disabled people may be discriminated against because the same rules apply despite being in a different situation. Regardless of this distinction, there is a second distinction to be made between direct and indirect discrimination. The ECJ has elaborated on this distinction as early as 1974, stating that “*the rules regarding equality of treatment forbid not only overt discrimination [...] but also all covert forms of discrimination which, by the application of other criteria of differentiation, lead in fact to the same result*”¹⁰⁰.

In essence, the ECJ ruled that discrimination is not a matter of formulating or drafting a policy but of its outcome.

Direct discrimination	Indirect discrimination
<ul style="list-style-type: none">• Rules are directly targeted at a protected group,<i>or</i>• Disregards that universal rules directly affect a protected group.	<ul style="list-style-type: none">• Rules are objectively targeted at a protected characteristic that is linked to a protected group, such as disabled people,<i>or</i>• Universal rules disproportionately affect a protected group because of their likelihood to show a specific characteristic.

Figure 18: Direct vs. Indirect discrimination according to ECJ

To break it down, the case of the unequal possibility of disabled people to move and reside freely within the EU thus shows a form of substantive, indirect discrimination. It is substantive because the same rules for free movement apply regardless of their higher poverty risk. It is indirect because freedom of movement is limited by reason of dependency on social aid, not disability as such.

Let us recall the initial question of this chapter: why are disabled people, de facto, still being discriminated against in this way? Part of the answer is that while formal, direct discrimination can easily be proven, concepts that ‘take into account the broader context’ or ‘link characteristics to a protected group’ muddy the water of where to draw the line between appropriate and discriminatory

¹⁰⁰ Case C-152/73 Sotgiu vs. Deutsche Bundespost

measures. For policymakers, it is therefore easier to define discrimination in a formal and direct manner. The ECJ, however, has proven that it is willing to recognise all the above-mentioned forms of discrimination, including indirect discrimination¹⁰¹. Regarding unequal treatment of women, for instance, the ECJ stated as early as 1990 that *“only women can be refused to employment on grounds of pregnancy and such a refusal therefore constitutes direct discrimination on grounds of sex”*.¹⁰²

The importance of that ruling lies in the fact that, for the first time, the ECJ did not require an actual comparator, which would have been a male job candidate, to recognize discrimination. Instead, it recognised causation as a sufficient ground. Thus, the Dekker case expanded the initial, formal approach to discrimination to the substantive approach. As De Vos has phrased it, *“Dekker can be seen to anticipate the contemporary EU law definition of discrimination as one person who is treated less favourably than another is, has been or would be treated”* (De Vos, 2020, p. 68).

Regarding discrimination on the grounds of disability, this ruling has been crucial. In one instance, a disabled son's mother was forced to leave her job over different views on her working hours. The ECJ, however, recognized the mother's responsibility to take care of her disabled son. Thus, even though she has not been disabled, she is still protected by the Equal Treatment in Employment and Occupation Directive, which prohibits discrimination on the grounds of disability in employment. On that ground, the ECJ ruled in July 2008 that disability discrimination by association is unlawful, too.¹⁰³

However, even if the ECJ has rejected the need for actual comparison, direct discrimination (at first hand or by association) still requires an immediate causality. In practice, this causality may often be highly difficult to prove, especially if something does *not* happen due to discrimination. Thus, the 'outcome' is the absence of a certain event. As for this thesis' case, it is nearly

¹⁰¹ A prominent example of this political attitude has been the former German transport minister Andreas Scheuer, who intended to introduce an Autobahn toll while reimbursing German nationals. Thus, it would indirectly disadvantage foreign drivers. After Austria and the Netherlands filed a complaint, the ECJ ruled in June 2019 that this unequal treatment contravened EU anti-discrimination law.

¹⁰² Case C-177/88 Dekker vs. Stichting Vormingscentrum voor Jong Volwassenen

¹⁰³ Case C-303/06 Coleman vs. Attridge Law and Steve Law

impossible to prove that the primary reason for a disabled person not to move abroad is due to his/her dependency on assistance and/or social aid.

The ECJ has recognized this problem in a case regarding the potential discrimination on the grounds of sex. *“In order to establish whether a measure adopted by a Member State has disparate effect as between men and women to such a degree as to amount to indirect discrimination [...], the national court must verify whether the statistics available indicate that a considerably smaller percentage of women than men is able to fulfill the requirement imposed by that measure. If that is the case, there is indirect sex discrimination.”*¹⁰⁴

This ruling is remarkable for two reasons. First, the ECJ rejected the necessity to ‘prove’ a discrimination in a particular situation but accepts the possibility of potential discrimination, if one group is likely to be affected “considerably”. Second, the ECJ refused to specify a specific percentage that is deemed to be considerable. Instead, it only requires the proof of potential discrimination based on statistics that show a correlation between the respective measure and the disproportionate likelihood of a protected group to be affected. For that reason, it is legitimate to declare the disproportionate exclusion of disabled people from moving and residing freely within the EU a discriminatory circumstance. (Barnard, 2014)

Recognizing this wide-ranging understanding of discrimination by the ECJ, a single EU anti-discrimination law could potentially have a significant impact. Nevertheless, the ECJ interprets the EU Equality Directives in a way that defines discrimination as one person being treated less favourably than another is, has been, or would be treated in a comparable situation. Thus, the actual or fictional comparator is still essential to recognize discrimination. Regarding disability, however, this requirement of a comparator complicates the issue. First, if other grounds for discrimination are edited, finding even a hypothetical comparator becomes increasingly tricky. Additionally, if disability is viewed as an individual’s impairment in the context of that person’s social environment and individual circumstances, the comparative approach is limited by definition.

¹⁰⁴ Case C-167/97 Seymour-Smitz & Perez vs. Secretary of State for Employment of the United Kingdom

2.1.3 The problem of multiple discrimination and disability in EU law

As if the different approaches to disability were not tricky enough to determine whether a disabled person is being discriminated against, it becomes even more complicated in cases of multiple discrimination. As the term suggests, 'multiple discrimination' refers to cases where discrimination occurs not only on one ground, but on multiple protected characteristics, such as disability *and* nationality. The term evolved in the late 1980s in the context of discrimination against black women in the United States (e.g., Crenshaw, 1989). Since then, it has developed into a concept recognised also by the European Institutions (e.g. EU Commission Special Report on Discrimination, 2007). However, in order to understand the problem of multiple discrimination in EU law, the concept has to be differentiated into three types:

Type	Successive discrimination	Cumulative discrimination	Intersectional discrimination
Characteristic	Occurs when a person is being discriminated against on different grounds in successive situations	It occurs when a person is discriminated against on different grounds in the same situation. In this case, the two forms of discrimination add up, creating an extra burden.	It occurs when a person is being discriminated against on two or more interacting grounds, and discrimination occurs because of this interaction.
Example	A wheelchair-bound Muslima applies for a job at a Christian welfare organization. Because there is no elevator at the tram station, she cannot use public transport to get to a job interview. Thus, she is being discriminated against on the grounds of disability. Subsequently, her job application is turned down because the employer requires membership in a Christian church. ¹⁰⁵ Thus, she is being discriminated against on the grounds of her religious beliefs. However, these two incidents are not directly connected.	A shared flat of students is looking for a new flatmate. The students like to party and drink alcohol. A young man who is diagnosed to be within the broader Autism spectrum applies for the room but is denied. The flat members feel uncomfortable with his need for a daily structure. Also, because he is still underage, he is not allowed to drink alcohol, which the students see as an additional reason to deny him. Thus, he is being discriminated against on the grounds of disability as well as age.	A stationary home for people with intellectual disabilities offers a young woman admission. However, for her to be admitted to the residence, the operator requires her to undergo surgery to be sterilized. ¹⁰⁶ The operators argue that, according to their experience, women with intellectual impairments are often not able to exercise birth control correctly, and the risk of having unwanted children in their institution would be too high. However, this compulsory sterilisation does not apply to their male residents of the same age, nor to elderly women who also have intellectual impairments. Thus, neither discrimination solely on the grounds of disability nor on the grounds of sex, nor age can be proven. However, the discrimination occurs because of the interaction of all three grounds.

Figure 19: Types of multiple discrimination (own depiction)

¹⁰⁵ In Germany, this was a common requirement to be employed by the Christian social service providers Diakonia and Caritas. It has been repealed not because it is discriminatory, but mainly due to a shortage of skilled workers

¹⁰⁶ According to a report by Uldry (2022), this practice is still legal in 13 EU member states, in some being a common practice.

Having outlined the different types of multiple discrimination, let us recall the ECJ's definition of discrimination as the "*application of different rules to comparable situations or the application of the same rule to different situations*" (ibid.). The question comes up when this definition can be applied, and when the interaction of multiple protected characteristics changes the situation to a degree that would justify unequal treatment. In theory, various situations become less comparable as more characteristics come into play. Thus, at some point, there would be different rules in different situations, and therefore, no one would be discriminated against.

While in successive and cumulative discrimination cases the instances could be drawn apart from each other and viewed separately, the problem becomes most visible in cases of intersectional multiple discrimination. As for the above-mentioned example of forced sterilization of a young woman in an institutionalized setting, this translates into the question of whether her situation is in fact comparable to those of young men. Suppose the answer to this question is negated. In that case, the subsequent question may be whether such an extreme interference with personal rights is a justified measure, but in the eyes of the ECJ, it would no longer be an issue of discrimination.

This leads to the following thesis: Cases of intersectional multiple discrimination are more difficult to regulate, because simple provisions such as the 'prohibition on grounds of disability' are insufficient. Moreover, cases of intersectional discrimination are difficult to prove. The problem that disabled people cannot exercise their rights as EU citizens equally to non-disabled people is essentially a form of intersectional discrimination. On the one hand, disabled people have a significantly higher risk of being dependent on social assistance. However, at the same time, they are only discriminated against if they have another EU citizenship and lose their right of residence. Consequently, the subsequent question must be asked in how far the EU member states are willing to deal with the question of how intersectional discrimination against disabled people can be prevented.

The distinction between forms of multiple discrimination can sometimes be difficult, especially between additive and intersectional multiple discrimination,

since it is mainly a matter of sequence. Nevertheless, some scholars have argued that a single anti-discrimination act would more likely provide better protection than the current accumulation of laws with different purposes (e.g. Bell, 2009; Hower, 2011). In practice, it would be much easier to claim discrimination on multiple grounds while referring to a single piece of legislation. Instead, the above-mentioned EU Equality Directives have “*created a hierarchy between the discrimination grounds, with better protection provided against discrimination on the grounds of race and sex than on the grounds of [...] disability*”. (Hower, 2011, p. 7).

Furthermore, when assessing the degree of harmonisation (which is this chapter’s subordinated aim), the ranking of EU anti-discrimination law requires not only the distinction between disability and other grounds for discrimination, but also the area where this discrimination occurs, such as employment or social security. The following table illustrates this asymmetry of protection from discrimination on different grounds in EU law.

Areas of discrimination	Racial and ethnic origin	sex	disability
Employment and occupation	Prohibited ¹⁰⁷	prohibited ¹⁰⁸	Prohibited ¹⁰⁹
Access to the supply of goods and services	prohibited	prohibited ¹¹⁰	Not prohibited
Health care	prohibited	Not prohibited	Not prohibited
Social security	prohibited	Not prohibited	Not prohibited

Figure 20: Hierarchy of protection against discrimination in EU law¹¹¹

¹⁰⁷ Directive 2000/43/EC (Art. 3.1.)

¹⁰⁸ Directive 2006/54/EC (Art. 14)

¹⁰⁹ Directive 2000/43/EC (Art. 13), Directive 2004/113/EC (Art. 12), and Directive 2006/54/EC (Art. 20)

¹¹⁰ Directive 2004/113/EC17 (Art. 3)

¹¹¹ Based on analysis by Hower, 2011, pp. 6-8

This juxtaposition shows how current EU anti-discrimination law has clear-cut gradations between the different grounds for discrimination to the disadvantage of disabled people. As for disability, the only legal protection from EU law is ensured in employment and occupation, and even this field is a theoretical, legal protection without comprehensive enforcement.

One example of the insufficiency of protection against discrimination of disabled people, even in the field of employment and occupation, is the practice of sheltered workshops: On the one hand, they provide a secure environment for disabled people who face difficulties finding a job in the so-called first labour market. On the other hand, only a fraction of disabled workers makes the leap from a sheltered workshop to regular occupation. While this has been the initial aim of sheltered workshops, they created a parallel, non-inclusive work environment that many in the public eye would falsely describe as daycare facilities rather than an occupation. Additionally, disabled workers experience discrimination in numerous ways, especially by exceptions in national labour laws. Germany, for instance, introduced its minimum wage law in 2014, however, explicitly excluding disabled workers in sheltered workshops by simply not classifying them as workers, but as “people in an employee-like legal relationship”¹¹². While for regular work a minimum wage of 12 €/hour applies, disabled people working in sheltered workshops are only entitled to a basic payment of 126 €/month.¹¹³

Another reason why protection against racial and ethnic origin discrimination, and sex discrimination, is stronger than the protection against disability is the functioning of supervisory bodies (However, 2011; Waddington; Broderick, 2018). EU law requires member states to designate supervisory bodies to ensure that equal treatment provisions based on racial or ethnic origin are implemented to have a protective effect.¹¹⁴ The same applies to discrimination on the grounds of sex, while the effect of their bodies may well be questioned.¹¹⁵ On the contrary, no such obligation is included in Directive

¹¹² German Social Code (SGB) IX, Art. 221 (1)

¹¹³ This basic payment can be raised by performance-based increments, however in practice the total salary in sheltered workshops rarely exceeds around 200,00 €/month.

¹¹⁴ Directives 2000/43/EC (Art. 13)

¹¹⁵ Directive 2004/113/EC (Art. 12) and Directive 2006/54/EC (Art. 20)

2000/78/EC regarding preventing discrimination against disabled people. This, however, is not due to a lack of demand. Spokespeople from disability lobby groups have been addressing the EU Commission to make corresponding proposals for a long time (experts 7 and 8).

Thus, there are at least two problems regarding multiple discrimination of disabled people: a theoretical and a practical one. First, a claim to be discriminated against on multiple, intersectional grounds is unlikely to be successful if only one ground is prohibited by EU law while the other is not. Second, even if both grounds are prohibited, the respective equality authorities are usually specialised in one field and may often feel unable to address the other.

Let us illustrate these two problems on one hypothetical example: A bar, located near a football stadium, is known for heavy drinking among male fans on game days. Occasionally, the bar owner observes harassing comments by his clients. When a woman with down syndrome wants to enter the bar, the owner fears that she could be sexually harassed and be unable to defend herself. He feels the need to protect her from his other clients, however he can't watch her the entire time in a crowded bar. Thus, for her own safety, he denies her access to the bar. Because she feels that she has been treated unfairly, she turns to the local Women's and Equal Opportunity Commissioner for help the next day.

According to EU law regarding the access of goods and services, discrimination on grounds of sex is prohibited, while on grounds of disability is not. However, since that person is discriminated against because she is a woman *and* disabled, this is a form of intersectional discrimination that EU law does not currently cover. Additionally, the Commissioner for Equal Opportunities may find it impossible to prove that the bar owner discriminates against women, since non-disabled women (as well as disabled men) are welcomed in his bar.

Since there is no obligation in EU law yet, most national legal systems of the member states do not include protection from forms of multiple discrimination (Howard, 2011, p. 9). Instead, the 'single ground approach' to discrimination is still predominant. Consequently, each case must be proven separately before a court, which heavily increases the burden for those being discriminated. In the

worst case, *“this approach could lead to a finding that no discrimination has taken place in cases of intersectional discrimination”* (Howard, 2011, p. 8)

There are several problems with the single ground approach to discrimination: First, it tends to emphasise differences between people. However, disabled people often do not want to be treated differently due to an emphasis on their disability. Additionally, the approach builds around the assumption that the line can be clearly defined. This may be an easy task for national affiliation with a passport, but it is undoubtedly not in the context of disability for the reasons explained in chapter 1.1. Even if in cases where it is possible to define this straight line, proving discrimination on grounds of disability in a single ground approach requires the existence of a formal disability status. However, many affected people, especially those whose disability results from some mental illness, refuse to apply for this status out of fear of being stigmatized.

A second problem with the single ground approach is the assumption that the ground of discrimination is part of the individual's identity and therefore (at least to a certain degree) unchangeable. Again, for disabled people, this is everything but without question, as their disability may essentially be the *result* of being discriminated, not the ground on which it takes place.

The third problem is that a single-ground approach to discrimination fosters simplifies potentially complex circumstances, as it forces to condense different groups under one alleged common characteristic. Howard points out that *“groups form around a single ground and are only interested in promoting provisions dealing with that ground. This tends to polarise groups, but it also assumes homogeneity within groups and does not give any attention to differences between individuals within the group.”* (Howard, 2011, p. 11). The complexity of defining disability in a way that includes physical, mental and intellectual impairments alike, is an excellent example for this problem. Thus, it is almost impossible to define an anti-discrimination measure on the single ground of disability that is appropriate for all groups.

Finally, applying a single ground approach to cases of multiple discrimination cases does not recognise the unique situation of the victim. Even when she/he is aware of the situation (which often is not the case), the victim ultimately must

choose on which ground the charges are made. In the previous used example, a disabled woman would have to choose whether she has been discriminated on the ground of sex or disability.

Because of these reasons, there has long been the demand by disability lobbyist to revise the EU anti-discrimination law¹¹⁶. Howard even argues, that *“the most effective way to achieve protection against multiple and intersectional discrimination across the EU would be action in an EU directive”* (Howard, 2011, p. 11 f.).

For that sake, the next chapter examines the latest attempts by the EU Commission to revise the existing anti-discrimination law.

2.1.4 The failed Equal Treatment Directive 2008

The previous analysis has illustrated why the tension between the medical versus the social approach towards disability has immediate consequences on the applicability as well as on the enforcement of anti-discrimination legislation. Additionally, it has been demonstrated that the EU has gradually expanded its understanding of discrimination over time, eventually formally incorporating indirect discrimination into secondary EU law.

It has furthermore been shown that the ECJ differentiates between unjustified discrimination (indirect or direct) and potentially justified unequal treatment. In many cases where claimants accuse the indicted party of discrimination, the ECJ must decide in this area of tension. However, regarding disability, European policymakers have acknowledged that disabled people are, in many cases, in fact discriminated against when moving abroad.

Nevertheless, the concept of multiple discrimination remains difficult, especially in cases of intersectional multiple discrimination. Multiple scholars have argued that the ECJ does not sufficiently take into account the severeness of reciprocal effects of intersectional discrimination (e.g. Onufrio, 2014; Schiek, 2018; Xenidis, 2020). Furthermore, a study conducted by the Danish Institute for Human Rights on behalf of the European Commission has recognized that in 2007, neither did EU equal treatment legislation make explicit provision to

¹¹⁶ All interview partners from European Disability Forum, Inclusion Europe, EASPD and Mental Health Europe emphasized the need for better protection against discrimination.

prohibit multiple discrimination, nor did most member states.¹¹⁷ (European Commission, 2007, p. 19). The researchers concluded that *“the EU and national anti-discrimination and equal treatment legislation should cover the grounds of age, disability, religion/belief and sexual orientation also outside employment and occupation, i.e. in the fields of social protection, including social security and healthcare, social advantages, education and access to and supply of goods and services which are available to the public, including housing. The new legislation must also provide provisions to address intersectional discrimination.”* (ibid. p. 53).

Such a change in EU legislation would strongly affect disabled people because the proposal named discrimination on grounds of disability in context of intersectional discrimination. Furthermore, it explicitly pointed out social security as well as social advantages and the access to social services to live an autonomous life - which are of high relevance regarding the factors for Active citizenship ‘security’ and ‘autonomy’ according to DISCIT (see chapter ‘the three levels of Active European Citizenship’). Following the conducted study, the European Commission has recognised the insufficient status quo of EU law and the need to deal with cases of multiple discrimination. For that sake it has brought forward a proposal for a new anti-discrimination directive in 2008.¹¹⁸

While previous anti-discrimination law has been passed comparatively quietly, the EU Commission's proposal from 2008 has been the beginning of a drama in policymaking with multiple acts. 15 years and three legislative periods later, the proposal has still not been adopted. For that sake, this chapter aims to identify the sociological thinking behind this proposal: What has changed compared to previous proposals? Why was the previous legislation no longer up to date? And why couldn't the member states reach agreement over a proposal concerning the equal treatment of their citizens, even though the issue has been placed on the political agenda by almost all Council presidencies for the past 15 years, often with a high priority?

¹¹⁷ In 2007, only Austria, Germany and Spain had included some provision regarding multiple discrimination in their national legislation. However, none of these three member states elaborated on the issue beyond a general provision.

¹¹⁸ Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation (COM/2008/0426 final)

The process that has followed the Commission's proposal is a perfect example that the idea of a "European Union of common values" may serve as a desirable goal, but it is by no means based on the presence of an already existing homogeneity of social norms.¹¹⁹ The debates in the European Parliament and especially within the Council have impressively demonstrates how different sociological views between the member states on disability and discrimination clash, and how discussions at the higher political level may shift from legal language to an intense discourse on the coexistence of people with and without disabilities. To explain this conclusion, the following paragraph will first analyse the idea behind the EU Commission's proposal from 2008 compared to previous anti-discrimination law. The subsequent analysis not only illustrates the different ways of thinking and approaches to disability within the EU that make harmonization so difficult, but also shows what happens in the European Council when delegations with different understandings of social coexistence of disabled and non-disabled people encounter.

The proposal for a directive on equal treatment of 2008

Almost two decades ago in 2006, the European Commission published a mapping study¹²⁰ on national anti-discrimination law in the EU. It was concluded that although there was a wide range of legislation in the member states on discrimination, there were significant differences in their material scopes. Additionally, the Commission identified an inconsistency regarding the grounds of discrimination that were covered by the respective national legislation. Interestingly, many national anti-discrimination laws applied to areas outside employment, which proved to become a difficult subject in the years following the 2008 proposal.

Essentially, the Commission sought to expand the scope of existing European anti-discrimination law to areas outside employment, given it the moniker of the "horizontal anti-discrimination directive", implying that it was no longer only applicable to the relations of dependence of employment. Referring to the

¹¹⁹ Procedure [2008/0140/APP](#)

¹²⁰ McColgan, A., Niessen J., and Palmer, F., "Comparative analyses on national measures to combat discrimination outside employment and occupation", Migration Policy Group and Human European Consultancy, Brussels, 2006

Treaty of Amsterdam, the proposal was aimed to cover grounds for discrimination such as religion and sexual orientation, but also age and disability.¹²¹

Complementing existing EC legislation in this area¹²², the proposed horizontal equal treatment Directive would prohibit discrimination in areas of high relevance to disabled people, including social security, housing, access to healthcare, education and, access to goods and services. Remarkably, the proposal included a separate article that focuses solely on equal treatment of disabled people.¹²³

Non-included, however, were the issues of multiple discrimination or the active promotion of equality. While *“this might be a strategically sensible choice with a view to limiting the range of contentious issues on the negotiating table, it is, though, a missed opportunity for modernisation”*. (Bell, 2009, p. 17)

This criticism has been shared by the European Economic and Social Committee (EESC) as well as the Committee of the Regions (CoR) whose opinions often serve as reference points during the legislative process. As such, the EESC¹²⁴. and the CoR¹²⁵ have published opinions on the Commission's Proposal for an Equal Treatment Directive.

Regarding the fight against discrimination on grounds of disability, the two committees recognized and supported the Commission's attempt to expand the scope of existing anti-discrimination law to areas outside employment. In general, the CoR is more restrained and less detailed in formulating its demands towards the Commission. That is mainly due to its composition of city majors and other regional politicians, who often have less capacity for EU politics than members of the EESC. Nevertheless, the regional and local administrative authorities play a crucial role in implementing disability-related policies, particularly those concerning social and health services (Kazepov, 2010). Expanding EU anti-discrimination law beyond the area of employment

¹²¹ Treaty of Amsterdam, Art. 13

¹²² In particular Council Directives 2000/43/EC, 2000/78/EC and 2004/113/EC.

¹²³ COM/2008/0426 final, Art. 4

¹²⁴ SOC/326 CESE 49/2009 – 2008/0140 (CNS), Rapporteur Mr. Crook, Retrieved May 2023.

¹²⁵ CoR 321/2008, 80th plenary session on June 17th – 18th, 2009.

could therefore have a direct (and potentially restrictive) impact on their governance. Yet, the CoR “*endorses the Commission’s renewed commitment*” and “*identifies non-discrimination mainstreaming and individual well-being as essential priorities*” (CoR 321/2008, 2009, para. 1 & 2). This shows the regions’ willingness to accept European guidelines to combat discrimination, even with the potential of limiting their own scope of action.

However, both committees also made clear that the proposal stayed far behind their hopes and expectations. The EESC even went as far as to state that “*the EESC believes that in certain areas the directive offers lesser protection than that which already exists under the race equality and gender directives.*” The strongest criticism concerned the proposed directive’s scope, which according to the EESC “*sets limits and allows wide exceptions that will undermine the effectiveness of the directive as a whole.*” (EESC, 2009, para.1.4.)¹²⁶ Thus, the Committee not only questioned the added value of the Directive, but even feared that it could undermine existing legislation. Considering the EESC’s reputation during the legislative process, this is a devastating estimation.

This concern over the directive’s scope is not the only concern shared by the CoR. The two Committees also pointed out the problem of different (legal) understandings of disability among the member states. Thus, they called upon a directive that promotes a uniform understanding of disability across the entire EU¹²⁷. The CoR indirectly criticized the Commission in pointing out that “*when establishing the existence of a disproportionate burden, the various needs of disabled people must also be taken into account, regardless of whether they are physical, mental, sensory or learning difficulties, as must the extent of their disability*” (CoR 231/2008, para. 27). Similarly, the EESC expressed its wish for a common understanding of disability that would be essential for “*the ability to provide preferential treatment [...] to persons with disabilities subject to the same justifiability tests*” (EESC, 2009, para. 3.1.2.1.) Therefore, both committees have pointed their fingers on the still existing unclarity on how ‘discrimination based on disability’ is to be interpreted in practice. As has

¹²⁶ This reference concerns in particular Article 3 of proposed directive COM/2008/0426 final

¹²⁷ EESC, 2009, para. 3.3.1.1

previously been explained, this has been (and still is) a key concern in context of free movement.

The criticism of the Commission's proposal by the two committees, however, did neither stop at the proposed directive's scope nor the questioning of a common understanding of disability. The previous chapter has discussed the problem of multiple discrimination, which is of particular significance for disabled people. In its statement, the EESC explicitly criticized that "*the directive fails adequately to address the issue of multiple discrimination*", (EESC, 2009, para. 1.7) adding its hopes that the EU Parliament and the Council would include further ideas on that issue during the legislative procedure. Similar concerns have been raised by the CoR which likewise pointed out that it has hoped for an attempt by the European Commission to address this issue.

How are these statements to be interpreted in light of the underlying question, whether a deeper integration of anti-discrimination law concerning disabled people is possible? First and foremost, the statements demonstrate, once again, the problem awareness among stakeholders. Furthermore, the EESC and CoR generally support the Commission's attempt to expand already existing equal treatment legislation to areas beyond employment, which would have been highly relevant to disabled people who are disproportionately unable to participate in the first labour market. Yet, the EESC and the CoR present themselves as the 'driving force' in this issue, pushing the EU institutions towards more integration. A key tool in their statements to influence the involved policymakers is the breakdown of general commitments into pieces that are more likely to have a legislative effect. Especially the problem of multiple discrimination and the lack of a common understanding of disability have, according to the EESC and the CoR, not sufficiently been addressed. Having analysed these viewpoints, the next section analyses how these calls have been perceived by the Council.

Discussions about non-discrimination of disabled people in the Council

When the proposal to renew the existing legislation on equal treatment has first been forwarded to the Council in 2008, the ministers held an initial debate¹²⁸: In that many ministers expressed were in favour of a more ambitious legislation. Several ministers claimed that their existing national legal systems already went beyond the Commission proposal, thus the new directive would have little effect within those member states. Others, while supporting the principle of equal treatment in general, questioned the need to establish EU rules in this area.

Yet, while there has been consensus to strengthen non-discriminatory measures on grounds such nationality, the discussion within the Council met its point of contention around the issue of discrimination on grounds of disability. On the one hand some delegations supported the demand by the EESC and the CoR to establish more ambitious provisions concerning measures to combat discrimination on grounds of disability. They underlined the importance of the proposal regarding the United Nations Convention on the Rights of Persons with Disabilities, which had been signed by all the member states. Most delegations, however, asked for certain parts of the proposal to be clarified to guarantee its legal certainty. This included clarifications regarding the proposal's economic and financial impact, but also the general question of who would be disabled under this Directive. Due to these concerns, after the first hearing the proposal has been blocked mainly by the German delegation¹²⁹

After the first Council Meeting, the European Disability Forum has been working with the Civil Society in Germany in order to dissolve the German blockade. However, concerns regarding a 'blurry' scope of the directive due to a lack of common definition of disability remained.

Two years after the initial proposal has been rejected, the Hungarian presidency started a new attempt to find consensus on anti-discrimination. It made clear, that the initial directive's aim was "*the protection against discrimination on the*

¹²⁸ 2893rd Council Meeting on October 2nd, 2008 in Luxembourg. Press Release retrieved in May 2023 from https://ec.europa.eu/commission/presscorner/detail/en/PRES_08_271

¹²⁹ Interestingly, at its first Council meeting on the issue the German delegation has been represented by the German federal minister for social affairs at the time, Ms. Ursula von der Leyen. After Ms von der Leyen became president of the European Commission in 2019, she expressed strong support for a renewed European anti-discrimination law.

grounds of religion or belief, disability, age or sexual orientation to areas outside employment, i.e. to social protection, social security and healthcare, to social advantages and education, and to access to goods and services, including housing."¹³⁰ Thus, the Council has been very aware of how the proposed Regulation was aimed at expanding non-discrimination onto the field of social policies. Interestingly, at this point of the debate no concerns regarding the principle of subsidiarity have been expressed.

However, not only did this not diminish concerns regarding a common understanding of disability, it added a second layer to the debate around the provision of 'reasonable accommodation'. Several delegations, including the German delegation, feared that enshrining 'reasonability' in EU non-discrimination law would open the door to bring the national or regional authorities before the ECJ over cases concerning accommodation of disabled people. The Council concluded that "*further discussion is needed on a number of outstanding issues*"¹³¹. Thus, instead of narrowing down the major points of debate to reach an agreement, the debate spread from the general question of 'who is disabled?' to the equally general question of 'what is reasonable?'

These questions had led to a dead end in the negotiations. Despite numerous accusations by interest groups as well as Members of the European Parliament, no agreement could be reached in the Council for more than 3 years. In January 2015, the issue of non-discrimination has been brought onto the Council's agenda who concluded that "*a large majority of delegations broadly supports the draft Directive*", however directly adding that "*further work [is] being nevertheless required on the provisions related to the division of competences between the EU and its member states and on clarifying the concrete obligations to be created by the Directive.*"¹³² Therefore, 7 years after the initial proposal by the Commission and despite the general support by a

¹³⁰ 3099th Council Meeting on June 17th, 2011 in Luxembourg. Press Release retrieved in May 2023 from https://ec.europa.eu/commission/presscorner/detail/en/PRES_11_176

¹³¹ 3131st Council Meeting on December 1st and 2nd, 2011 in Brussels. Press Release retrieved in May 2023 from https://ec.europa.eu/commission/presscorner/detail/en/PRES_11_471

¹³² 3357th Council Meeting on December 11th, 2014 in Brussels. Draft minutes retrieved in May 2023 from <https://data.consilium.europa.eu/doc/document/ST-16887-2014-INIT/en/pdf>

large majority of member states, a handful of delegations blocked the proposed directive with concerns over the subsidiarity principle.

Three further years later in November 2017 a progress report¹³³ conducted by the Council illustrated how divided the delegations have become. While “*some delegations would have preferred more ambitious provisions regarding disability*”, others questioned the legal basis for the Commission’s proposal, which they regard as “*infringing on national competence for certain issues and as conflicting with the principles of subsidiarity and proportionality*” (Council report 14867/17, p. 2).

Likewise, many delegations supported the inclusion of the concept of multiple discrimination in the draft Directive, including cases in which *multiple discrimination could also occur through the combination of two or more grounds, which taken separately would not give rise to discrimination against the person concerned* (Council report 14867/17, p. 4). In contrast, two unnamed delegations¹³⁴ rejected the inclusion of multiple discrimination, citing doubts regarding its practicability as well as general reservations on the proposal.

The latest attempt to break this deadlock has been conducted by the Czech Council presidency in 2021.¹³⁵ Recognizing that all of the above mentioned concerns around the scope, the impact, reasonable housing and the subsidiarity principle resulted from different views on disability, the Czech delegation proposed the option for member states to ‘temporarily exclude’ disabled people from the directive, in particular the requirement to take ‘adequate measures’. This proposed compromise, however, resulted in an open dispute in the Council, in which most delegations made clear that in their view, such an exclusion would be in sharp contrast with the UNCRPD. Only the German delegation stated that the “*flexibility was necessary to cope with the financial burden resulting from the disability provisions of the Directive*” (p.4), supported by some others who reinforced their concerns on the potential violation of the subsidiarity principle.

¹³³ https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CONSIL:ST_14867_2017_INIT

¹³⁴ According to the interviewed expert from the Council Working Party on Social Questions SQWP (expert 5), one of the two delegations has been from the German government.

¹³⁵ https://eur-lex.europa.eu/legal-content/DE/TXT/PDF/?uri=CONSIL:ST_13070_2022_INIT

However, at no point in time did this promised compromise have a chance. Not only did multiple member states make clear, that they would not agree to this compromise, also the Commission announced that before excluding disabled people from the scope of the Directive, it would rather withdraw its proposal all together.

The European Parliament

Contrary to the Council, the European Parliament has voted in favour of the draft directive multiple times between 2009 and 2015.¹³⁶ In response to the blockade in the Council, the Parliament has conducted various attempts to pressure the Council to act. In an oral questioning of the European Commission, the Parliament not only asked for concrete steps to be taken by the Commission to overcome the blockade, but it also brought the so-called 'passarelle clauses'¹³⁷ into the discourse. This is a remarkable step, because the passarelle clauses could (in theory) break the resistance of a few member states over such a far-reaching topic as non-discrimination by a qualified majority in the Council. The Parliament's Research Service has called the passarelle clauses "*opportunities for more flexible supranational decision-making*"¹³⁸. On the one hand, this step has very little chances to succeed, because due to its parliamentary democracy the German government is appointed by the 'Bundestag' - which could veto any attempt to bypass the German government's blockade in the Council. The Commission itself made clear that it had investigated the possibility of the passarelle clause as well as the possibility of 'enhanced cooperation' according to Article 20 TEU but concluded that "*Article 19 TEU remains the only conceivable legal basis for preventing discrimination.*" (EU Commissioner for Equality Helena Dalli)¹³⁹. Nevertheless, the on dossier on non-discrimination and equal treatment demonstrates that the

¹³⁶ The latest resolution on this dossier has been adopted by the plenary on November 22nd, 2014.

¹³⁷ The 'passarelle clause' according to Art. 48 (7) of the Treaty of the European Union enables the European Council (the heads of government) to decide unanimously that certain policy areas for which unanimity is required in the Council of the European Union can be decided by qualified majority. However, in this case, the national parliaments are given a right of veto, and thus, the Council may block the decision.

¹³⁸ Title of a Study by the European Parliamentary Research Service (EPRS), December 2020

¹³⁹ Helena Dalli, EU Commissioner for Equality at the European Parliament plenary session on March 15, 2023, referring to the role of the Court of Justice to rule on cases provided for in the EU Treaties

majority of the Members of Parliament as well as the European Commission is willing to examine the possibilities to shift competences regarding non-discrimination and equal treatment from national to EU level.

Regardless the political will, the blocking of the proposal within in the Council by a minority of national governments, particularly the German delegation, illustrates the limited impact of this driving force. The debate at the previously cited plenary session between the Commission, the Parliament and the Council's Swedish presidency has not been short of frustration of the delegates from all institutions. The Swedish Minister for EU Affairs expressed the support of her own government, however also made clear that "*the presidency does not expect any decisive breakthrough any time soon*".¹⁴⁰ Shortly after this remark, a Member of Parliament requested her colleagues to freeze the household for the Council altogether until a compromise is reached.¹⁴¹ Even the far-right Susanna Ceccardi disclosed the paradox of the concerns by the blocking delegations that "*on the one hand the proposed directive contains too many classifications, on the other hand there are not enough*"¹⁴², pointing out that individualism cannot be classified in tables.

Recalling the underlying research question of this thesis whether citizens' rights can be a driving force to further reform and harmonize the European social system from a charity-based understanding towards a right-based approach, the example of the Equal Treatment Directive is affirmative. The dossier illustrates that most MEPs, the Commission as well as most national governments support the strengthening of EU legislation in favour of ensuring disabled people citizens' rights. Furthermore, both the Commission as well as the Parliament consider the "*opportunities for more flexible supranational decision-making*" (ibid.) to break the vetoing power within in the Council over an issue concerning citizens' rights.

¹⁴⁰ Jessika Roswall. Swedish Minister for EU Affairs at the European Parliament plenary session on March 15, 2023

¹⁴¹ Sophia in 't Veld, MEP, Renew Europe fraction

¹⁴² Susanna Ceccardi, MEP, Identity and Democracy Group

The chapter on non-discrimination of disabled people followed the question of whether this policy field could potentially shift competencies from the national to EU level. There is a crucial difference between unequal treatment and discrimination, which the ECJ defines as the “*application of different rules to comparable situations, or the application of the same rule to different situations*”. Furthermore, the ECJ has clarified that the EU’s existing law includes protection from indirect discrimination and rejected the necessity to ‘prove’ a case of discrimination in a particular situation. Instead, it accepts the possibility of potential discrimination if one group is likely to be affected “considerably”. Regarding the research question of disabled people’s ability to move and reside abroad, the potential discrimination results from applying the same rules to disabled and non-disabled people, despite disabled people’s higher poverty risk.

However, there is a wide consensus among the EU institutions that the issue of multiple discrimination, particularly intersectional discrimination, is insufficiently covered by existing EU legislation. The barriers which disabled people face when wanting to live abroad are the result of such an intersection of two protected grounds, namely nationality and disability. Additionally, there is a crucial difference between discrimination on the grounds of disability compared to other protected grounds: Disability has commonly been viewed as a problem that needs solving, not a characteristic that needs protection. This difference has led to a directive to expand EU non-discrimination legislation horizontally to all policy areas, to be blocked for more than 15 years in the Council. The main point of contention is the unsolved question on how to assess disability (see chapter 1.1). Remarkably, this blockade consists of a small minority of delegations, particularly the German delegation.

The debates around the EU’s equal treatment directive have been highly emotional. Remarkably, the European Commission and the EU Parliament have assessed possibilities for ‘supra-national decision-making’ to overcome the blockade in the Council. Thus, despite the resistance of a few delegations in the Council, the answer to this chapter’s question is to be affirmed.

2.2 The security dimension: Social security

“Social security is not an island beyond the reach of EU law”

- ECJ Advocate General Giuseppe Tesaurò -

Having laid out the potential consequences of understanding access to social systems as a right rather than a societal generosity, the following chapter will assess whether this changes how the EU member states coordinate their social systems.

The growing tension between individual rights as European citizens on the one side versus national solidarity on the other has been observed by many scholars before. Naturally, the question arises of whether citizens' rights may pave the way for a European social system. On the one side, some argue that member states are only willing to give up sovereignty as an investment with significant revenue (e.g. Scharpf, 2008; Hemerijk, 2013). Scharpf regarded the individual's power to influence the European social model as limited:

“I still consider the European reconstruction of the welfare state, or even just the European harmonization of national social regimes, especially after the eastward enlargement, to be absolutely without a chance” (Scharpf, 2008, p. 94).

His argument is primarily based on two assumptions: First, the welfare systems are mainly static, at least to the degree that the respective (national) society is willing to accept changes to their welfare system. Secondly, Scharpf views welfare policies, including social security systems, as a necessary cost to cope with the adverse effects of an otherwise functioning economic system. From a legal standpoint of the status quo, Scharpf is right. The interesting question is, however, whether his statement from 2008 could be outdated. A decade later, even the national governments agreed in the Council on the necessity to work together in social affairs:

“Social security systems in the EU are not harmonized. Every member state can decide who is insured under their legislation, what benefits they are entitled to

and what the conditions of access are. However, to ensure that the free movement of people is possible in practice, the national social security systems need to be coordinated” (Council Press Release 371/18, 2018, p. 2).

Thus, the focal point is the potential for further development of this coordination. To further assess this thought, it helps to categorise welfare policies into three layers, from providing security schemes if something unforeseen might happen in the future (e.g. social security), giving aid in the exact moment that someone faces a problematic situation (e.g. sickness), to assistance in permanent or long-term situations (e.g. childcare). Essentially, all these layers have a common ground: strengthening the workforce. When a worker becomes sick, welfare policies provide the treatment so that she/he can re-enter the workforce as soon as possible. The same applies to social policies such as maternity leave or childcare. Social security has the effect that workers are willing to take greater economic risk, for example, taking another job, investing in new business models, etc.

The underlying thought of all these social aids is that, in the long term, society will benefit from these systems, not only on an abstract level in terms of a stronger societal affiliation, but also monetarily. Rather than a fixed cost to society as Scharpf saw them back in 2008, today social systems may be seen as an investment (e.g. Streeck, 1999; Hemerijk, 2013). Moreover, as with investments in general, the decision of whether to invest is based on risk assessment. Therefore, the increased coordination (or harmonisation) of social systems becomes a question of whether the potential gain outweighs the risks. However, each member state must answer this question for itself.

One of the voices favouring a joint European social policy system is the sociologist Claus Offe (2000). Unlike Scharpf, he does not deny the possibility of further harmonisation of social policies in Europe. However, he argues that it would require a different approach: *“The changing patterns of work within Europe suggest the need for social policy in the EU as a whole to break from work-based entitlement to a citizenship entitlement of basic income or social dividend”* (Offe, 2000).

Offe certainly has a valid point, considering that until now, the European Commission's strategies to combat social exclusion have been to bring those affected into the labour market (e.g. by Abberley, 2002). In terms of enabling disabled people to work, these strategies mainly focus on accessibility and decreasing barriers. In a world following the social model of disability, however, strategies to combat social exclusion would require a change in the labour market itself, not only in access to it.

To summarize the key questions concerning the coordination of social systems in the EU in the context of the research question:

- Are social systems seen as a necessary cost or as an investment?
- If they are seen as an investment, is labour the only criterion on which a risk assessment is based?
- How does this translate into European regulations on the coordination of social security?
- What are the consequences of these regulations on disabled people's possibility of moving abroad?
- Can the civil rights of disabled people who are excluded from the labour market foster the development of a less work-based approach?

The following paragraphs will assess these questions by examining the development of social policy coordination in the EU, focusing on how cash transfers differ from other areas. Furthermore, the analysis includes the key points of contention regarding the Commission's 2016 proposal to amend the existing legislation on the coordination of social security systems.¹⁴³

2.2.1 Coordination vs. harmonization of social security benefits

To assess these questions, this chapter addresses the core issue at stake: the coordination of the (national) social systems of the EU member states. When discussing coordinating social policies, it is important first to understand what coordination itself implies, its chances, and why it may be problematic in certain circumstances.

¹⁴³ Regulation (EC) No 883/2004 on the coordination of social security systems and regulation (EC) No 987/2009 laying down the procedure for implementing Regulation (EC) No 883/2004

In general, “*coordination [of social policies] refers to the rules that intend to bridge the differences between social security schemes and the differences between national and international regulations (...)*.” (Pennings, 2015, p. 321). Thus, coordination does not necessarily include the gradual alignment of different systems or even their harmonisation, which, according to Scharpf, is “*without a chance*” (Scharpf, 2008).

Pennings illustrates the difference between coordination and harmonisation with a good example: Assuming that a person is moving within the EU, and that the host Member State would require one year of employment to be eligible for unemployment benefits, whereas the state of origin requires only six months. Coordination between the social systems might take the time of unemployment at the state of origin into account when assessing a person's eligibility. The differences in legislation, however, remain. Thus, it does not guarantee that adverse effects will be compensated.

As for the harmonization of social security systems, the EU treaties give no legal basis for the EU Commission to act, at least not until a significant change in EU primary law is made. The coordination of social security schemes, in contrast, has gradually progressed since the 1970s and has been formally established in the Lisbon Treaty:

“The European Parliament and the Council shall (...) adopt such measures in the field of social security as are necessary to provide freedom of movement for workers (...) and their dependants.” (Art. 48 TFEU).

In this light, if freedom of movement is not limited, there is no intersection between the national social security systems or between social policy and EU law. However, if freedom of movement is, in fact, limited because a certain policy affects another, policy coordination essentially means coordinating the implementation of national systems (not their alignment).

In federal systems, where the various layers of governance hold a certain degree of power and autonomy, coordination between these layers is essential. This is referred to as *vertical* coordination. A great deal of vertical coordination concerns the subsidiarity principle, meaning that the power to implement a particular policy should be on the lowest possible level. It has been argued that

this form of vertical coordination has led to the European Union becoming a federal structure. (e.g. Bolleyer & Börzel, 2010; Peters, 2018).

In contrast, horizontal coordination is needed if one layer holds most power. However, the layer itself is fragmented. A classic example of this is the education policy area in Germany, in which the German states (Bundesländer) hold the competence. While it is agreed upon that common educational standards are needed within Germany, there is no common public will to harmonise the different education systems by transferring competences to the federal government. For that sake, coordination between the federal states occurs horizontally at a permanent institution.¹⁴⁴

The situation can be compared to the EU's coordination of social security systems. As long as social security remains a competence of EU member states, member states decide which risks they want to set up a social security scheme for. This includes the eligibility criteria and financing tools. Therefore, regarding the social security for disabled people in cross-border situations, the horizontal agreement between the host Member State and the home Member State is indispensable.

To foster this horizontal coordination of social protection and social inclusion policies between its member states, the EU has established the so-called 'Open Method of Coordination' (OMC) as early as 2000. OMC is a form of intergovernmental policymaking. However, it does not include binding EU law; thus, member states are not obliged to change their existing legislation. It is, therefore, best categorised as a form of 'soft' law (Hemerijk, 2002). Following its establishment, many scientists (e.g. Ferrera, 2005; Zeitlin, 2009) researched the success of OMC, particularly social inclusion and its effects on the integration of social policies, some concluding that "*the OMC in social protection and social inclusion have helped to disseminate new European concepts and to challenge taken-for-granted assumptions in even the best-performing member states*" (Zeitlin, 2009, p. 19).

In the field of disability, this includes not only eligibility criteria but also the question of how to define disability. While this indicates what OMC has to offer,

¹⁴⁴ This permanent institution is called "Kultusministerkonferenz".

it is not legally binding, which results in a strong dependency on political will. As Zeitlin formulated, *“the influence of OMC processes on national social and employment reforms depends partly on domestic institutional and political conditions, notably variations in popular/public attitudes towards the EU (integrationist/Eurosceptic)”* (Zeitlin, 2009, p. 19). That said, European politicians have been cautious about testing the public attitude towards a European social reform, especially with the rise of populist parties in many EU member states.

However, next to the hierarchy of the acting authorities involved, another aspect to consider is the form of coordination. According to Scharpf, coordination occurs when decisions made in one program or organisation consider those made in others and attempt to avoid conflict (Scharpf, 1994). This can be called *negative coordination*. In contrast, *positive coordination* requires the involved actors to be rather proactive with the goal not only not to harm the status quo, but to improve it. Thus, *“positive coordination would require the organisations to go beyond simply avoiding conflicts and to seek to find ways to cooperate on solutions that can benefit all the organisations involved, and their clients.”* (Peters, 2018, p. 2).

Horizontal coordination	Vertical coordination	Harmonisation
Negative coordination	Positive coordination	

Figure 21: Coordination vs. Harmonisation of social policies

Regarding systems of social security within the EU, the potential conflict results from the right to freedom of movement of its citizens, which is limited to disabled people who are dependent on social aid. To claim this right, positive coordination between the social systems has a greater effect. Regarding the broader question of how the EU can improve the possibility for disabled people to move abroad, the degree of vertical integration is decisive. The question thus is: How is the development of the coordination of the national social systems to be classified in this scale?

However, it is important to point out that the distinction between harmonisation and coordination is not always as clear-cut as it first might seem, namely when

the policy field concerned interferes with other policy areas. In political science, this is often referred to as the spill-over effect that may occur intentionally, but also unintentionally. Especially EU rights on free movement and equal treatment influence the member states' obligations to provide social security. As ECJ advocate General Tesouro has formulated, “*social security is not an island beyond the reach of EU law*”¹⁴⁵ (ECJ Advocate General Tesouro, 1998). This statement is based on the premise of labour in Article 48 TFEU, which already empowers the EU institutions to take measures in social security to ensure freedom of movement for migrant workers. Consequently, the field of tension shifts from those who have competence over the social security system to those who enjoy the right to freedom of movement (Golyner, 2020).

While the ECJ has demonstrated in the *Pinna* case that it had no intention of challenging the distinction between coordination and harmonisation (which would exceed the ECJ’s competences)¹⁴⁶, it instead acknowledged differences in the social security schemes. In the same ruling, however, the court also stressed the principle of equal treatment and the prohibition of discrimination based on nationality. The impact of the *Pinna* judgement has been analysed by many legal scholars, some of whom concluded that “*the application of the Treaty’s equal treatment provision has a certain harmonising effect*” (Pennings, 2015, p. 322). Martinsen (2013) likewise points out that the ECJ application of EU law regarding equal treatment pressures national social systems, in particular those that are contribution-based.

For that sake, to distinguish between vertical coordination and harmonisation, the role of the ECJ is crucial for the subsequent analysis.

Social security: Investment or burden?

To trace back to how the coordination of social welfare systems in Europe has been regarded, one must look back to 1971, when the Council realised the first regulation on this matter: Council Regulation (EC) 1408/71 on the application of social security schemes to employed persons, self-employed persons and to

¹⁴⁵ Joined Cases C-120/95 *Nicolas Decker v. Caisse de malade des employés privés* and C-158/96 *Raymond Kohll v. Union des caisses de maladie*, paragraph 17

¹⁴⁶ F. ex. in the Case 41/84 *Pietro Pinna v. Caisse d'Allocations Familiales de la Savoie*, January 15th, 1986

members of their families moving within the Community. Not only did the European Community acknowledge for the first time that the movement of workers between the member states is subject to their own social safety, but the scope of the regulation also included family members (Art. 2) as well as subject areas such as invalidity and old-age benefits (Art. 4). Most remarkably, the member states agreed that *cash*-benefits deriving from invalidity or old-age should, in principle, not be reduced or withdrawn when the entitled person resides in another Member State (Art. 10). However, when it came to providing services to disabled people or of those in need of care, the regulation has been far from precise. First, unlike the aforementioned cash benefits, the regulation does not clarify entitlements for disability-related care or assistance services.

The apparent lack of readiness to work towards a joint social security system was manifested over a decade later by the ECJ in a case concerning the supply of medicines¹⁴⁷. The ECJ's ruling clarified that "*community law does not detract from the powers of member states to organise their social security systems and to adopt, in particular, provisions (...) to promote the financial stability of their health-care insurance schemes*" (paragraph 16).

This ruling is remarkable for several reasons. First, although the case concerned the supply of products, the ruling included providing services without any distinction between these two economic sectors. However, this equalisation is based on the idea that services are 'consumed' in the sense of being dispensable - a highly problematic notion regarding social services. Second, the ECJ connects social security systems with healthcare in its ruling. It is characteristic of that time to view the need for care or assistance resulting from medical sickness, which aligns with the medical approach to disability. Consistently, this approach focuses on the treatment and ideally, the curing of that illness. However, because disabled people, as well as elderly people in need of care, do not (only) need to be treated, this approach often fails to fulfil their actual needs. At a later stage, this distinction became crucial, especially regarding disabled people.

¹⁴⁷ Case 238/82 Duphar vs. The Netherlands (1984). To secure the financial stability of the national Ziekenfondsverzekering (sickness insurance fund), the Dutch government took measures to regulate the use of medicines as well as the export of medicines within the European Community.

Furthermore, it is remarkable that the ECJ's main argument is not that healthcare, as part of the national social security system, remains within the member states' responsibilities¹⁴⁸, but it explicitly named financial stability to confirm the member states' power over organising their social welfare systems. Again, just as the European Commission did in the early 1970s, the ECJ made it clear that it viewed social systems as a financial burden to society and not an investment. For example, according to MEP Langensiepen, there is almost universal concern about the shortage of skilled workers within the European Parliament. However, no connection is made to include disabled people better in the workforce (expert 3).

Principles for the coordination of social security schemes

To sum up, the difference between harmonisation and coordination of social security systems is crucial to understanding the EU's approach to the ESM. While there is no legal basis for top-down harmonisation of national social policies, their coordination may occur in different forms and layers.

Furthermore, despite some scholars arguing for changing the viewpoint on social security, welfare policies have traditionally been linked closely to labour. Not only do EU policies on combating social exclusion aim at bringing people into paid labour, but it is also the primary criterion for those in need to be eligible for social aid. As for disabled people, this results in a 'benefit-trap', meaning the general ability to work means a loss of income subsidies, even though disabled people do not have the same chances on the labour market compared to non-disabled people. According to a member of the EESC's permanent group on disability rights, the potential loss of disability-related benefits prevents many people from taking up paid labour (expert 6).

The following paragraph addresses how this translates into European regulations on the coordination of social security, because "*this coordination system is of particular importance for persons with disabilities. (...). Proper social security coordination is of the utmost importance to ensure that individuals with disabilities can exercise their free movement rights on an equal basis with others*" (van der Mei, 2020, p. 165).

¹⁴⁸ Later manifested in Art. 168 (7) TFEU regarding the provisions on public health

The most relevant legislation to understand the Status Quo regarding the European social security model is Regulation (EC) 883/2004 on the coordination of social security systems¹⁴⁹ (Golyner, 2020). In line with the ECJ's rulings, the regulation manifests that the member states decide on the key aspects of social security, particularly the decision on who is entitled to social benefits, the form of benefits and services, as well as the necessary conditions for entitlement. However, in an attempt to improve social security in cross-border situations, the regulation lays down five general principles on the coordination of the national security systems:

- The principle of equal treatment/non-discrimination (direct or indirect) on grounds of nationality (Art. 4)
- The principle of equality of benefits, income, facts or events, meaning that when moving to another Member State, the social security entitlements of that person in their country of origin must be considered (Art. 5)
- The principle of aggregation of periods of insurance, employment (including self-employment) or residence when calculating the entitlements in another Member State (Art. 6)
- The principle of single applicable legislation, setting the general rule that a person should only be subject to legislation of one Member State at the time (Art. 11)
- The principle of exportability, which generally allows entitled persons to receive their cash benefits in another Member State (Art. 7).

It is remarkable that the first principle directly links the coordination of social security policies to the field of non-discrimination. However, it refers to discrimination on grounds of nationality, not on grounds of disability. While in other EU legislative documents these two are commonly named interchangeably in the same paragraph, this is not the case in Regulation 883/2004.

Secondly, it is likewise remarkable that the Regulation generally establishes the exportability of cash benefits as the norm, not the exception. Considering that dependency on social assistance often results in the loss of the right to reside in

¹⁴⁹ The Regulation is complemented by Regulation (EC) 987/2009 laying down the procedure for implementing Regulation (EC) No 883/2004 on the coordination of social security systems

another Member State, the question arises whether disability-related benefits are explicitly excluded from the scope of this principle.

To further assess this question, let us assess the provisions regarding disability as laid down in Regulation 987/2009, whose aim is to implement the above-mentioned principles on social security coordination.¹⁵⁰ Again, this goes back to whether disability is viewed as a burden to society or the result of an inaccessible environment. In that context, Art. 2 of the amending Regulation foresees that *“(...) exchanges between member states’ authorities and institutions covered by the basic Regulation shall be based on the principles of public service, efficiency and active assistance, rapid delivery and accessibility, (...), in particular for the disabled and the elderly.”*

Although focusing solely on administrative and procedural questions in the context of the coordination of the social systems, the wording regarding the exchanges between member states is remarkable. While it demonstrates not only problem-awareness but the general willingness to work towards better coordination in matters of disability-related benefits, the legislators also point out the danger that, due to the nature of their needs, affected people might be deprived of their rights while being caught in complicated and non-transparent administrative procedures.

That said, Regulation 883/2004 and its successor missed the chance to include further provisions regarding disability to follow up on their intention. Instead, it must be concluded that, *“within the EU and its member states, there is no specific social security scheme referring to disabled people. On the contrary, disability has for a long time been part of other policy areas such as health insurance”* (Kohlbacher, 2015, p. 285). Thus, despite problem-awareness and good intentions, ‘positive coordination’ in the aforementioned understanding of the term does not take place regarding the social security of disabled people. The following paragraph, therefore, focuses on the possibility of negative coordination by analysing EU legislation regarding income benefits that may not

¹⁵⁰ Regulation (EC) No. 987/2009 laying down the procedure for implementing Regulation (CEC) No. 883/2004 on the coordination of social security systems. Published in the Official Journal of the EU on October 30th, 2009, Volume L284/1

be primarily set up for disabled people, but which may affect them in many cases.

2.2.2 Income benefits related to disability

The missing provisions regarding disability on the one hand, Regulation 883/2004 for the first time included provisions on social benefits in cases of illness as well as in cases of invalidity (Art 3.1). Essentially, "*the relevant chapters of the Regulation apply to income-replacing benefits that are granted to persons whose ability to work and generate an income is reduced by a physical or psychological impairment*" (van der Mei, 2020, p. 165). Regarding the coordination of sickness benefits, the provisions are laid out comparably straightforward in Art. 17 of the Regulation. According to this article, while sickness benefits are awarded by insurance and governed by the member states, they do not depend on where the respective person becomes sick. In other words: "*sickness benefits are exportable*" (ibid.)

The distinction between sickness and invalidity is crucial for social security benefits for disabled people because national regulations on these matters differ. While in some member states, the social security systems for sickness and invalidity are not only separate (e.g., in Germany) but even mutually exclusive, other member states apply those two chronologically.

Again, the key difference regarding the social security of disabled people in cross-border situations is the duration of the person's inability to work. While Article 17 addresses the coordination of social systems in cases of short-term sickness, the notion of invalidity in that regulation assumes a long-term or permanent inability to work.

However, neither of these concepts is defined in that regulation. Thus, the central questions are: Are disabled people who need care ill? And does 'invalidity' include innate disabilities?

The ECJ has dealt with this important distinction in the case of Lucy Steward, a British national born with Down's Syndrome, who has lived in Spain with her parents since she was 11 years old. The British government has paid her

disability-related living allowance¹⁵¹. On her 16th birthday, Lucy's mother, as her daughter's appointee, claimed a short-term incapacity benefit in youth. This claim has been refused not only because the granting would require permanent residence in Britain, but also because Lucy did not meet the criteria of illness. The case has been brought before the ECJ to clarify the terminology in respect to the coordination of social security measures:

“In order to distinguish between different categories of social security benefit, the risk covered by each benefit must also be taken into consideration. (...). A sickness benefit covers the risk connected to a morbid condition involving temporary suspension of the concerned person's activities. By contrast, an invalidity benefit [...] is intended, as a general rule, to cover the risk of disability of a prescribed degree, where it is probable that such disability will be permanent or long-term.” (European Court of Justice, 2011, para. 36-38)¹⁵²

By linking the risk factor to the distinction between invalidity and sickness, the ECJ has unintentionally laid its finger on another problem regarding coordinating these security systems. While some member states have chosen risk-based systems, others have chosen systems based on accrual. The crucial difference here is the duration of insurance. In a risk-based system, the person must be insured at the moment when the risk of invalidity materializes. However, the amount received does not depend on how long that person has been insured. In contrast, in an accrual-based system, the longer someone has been insured, the higher the benefit to be received (van der Mei, 2020, p. 166).

The ECJ's ruling answers two questions of this chapter: First, it illustrates that social services are not seen as a cost in general, but they are indeed seen as a form of investment. For that sake, the ECJ stresses the need to take the risk assessment into account. Second, this risk assessment is not only built on one criterion but two, namely labour and time. While this does follow a certain logic, it is also highly problematic for disabled people, because in practice, this means that the decision whether a person is eligible for (exportable) sickness benefits or (non-exportable) invalidity benefits, depends on an estimation of whether the

¹⁵¹ In accordance with Regulation No. 1408/71, Art. 95b.

¹⁵² Case C-503/09 Lucy Steward v Secretary of State for Work and Pensions, 2011

person will be able to work in the future. As for the case of Lucy Steward, for instance, the ECJ itself stated that she *“has never worked and, in all probability, will never be able to”* (European Court of Justice, 2011, para. 20). This, however, is inconsistent with the ECJ's own definition of disability in the Chacón Navas case, according to which the individual circumstances should be decisive (see chapter 1.1.3.)

It is remarkable that, in accordance with Regulation 883/2004, the ECJ not only follows the person-centred medical model of disability but also supports labour-connected eligibility criteria. That said, the strong connection between social security and labour becomes apparent.

2.2.3 The dividing line: Special non-contributory cash benefits

Having identified the factors of risk and labour as the key criteria for the exportability of social security benefits, the follow-up question is how this dividing line is reflected in legal terminology. To answer this question, we must look back to 1971, when the member states agreed on the aforementioned Regulation (EC) 1408/71 regarding social security protection for workers within the EU. This regulation introduced the term ‘special non-contributory benefits’ (Art. 4), which were to become crucial in the subsequent 2004 Regulation, including the following definition:

“special non-contributory cash benefits’ means those which are (a) intended to provide [...] solely specific protection for the disabled, closely linked to the said person’s social environment in the Member State concerned and (b) where the financing exclusively derives from compulsory taxation intended to cover general public expenditure and the conditions for providing and for calculating the benefits are not dependent on any contribution in respect of the beneficiary” (Regulation 883/2004 Art. 70.2).

Thus, the differentiation between risky expenses for social assistance and reasonable investments in the labour force is classified by whether the respective person has previously contributed to the budget for these expenses. A good example of the latter is long-term care benefits that derive from contributions to care insurance. On the other hand, disability-related social security benefits fall under the category of non-contributory cash benefits.

Essentially, this differentiation addresses the relationship between the beneficiary and the providing institution. In contribution-based social security schemes, this relationship is equal. In non-contributory cash benefits, this relationship is hierarchical, with the beneficiary dependent on charitable obligations.

However, why have the EU member states drawn a line at the contribution to insurance regarding social security? One reason could be that *“people and politicians are attached to the myth of personal rights following from the insurance principle”* (Vonk, 2020, p. 141). In other words, the way of thinking is that certain benefits are only granted in return for contributions, including the exclusive right to receive social security benefits while residing in another EU Member State.

While these contribution-based benefits are in general exportable, *“special non-contributory cash-benefits shall be provided exclusively in the Member State in which the persons concerned reside, in accordance with its legislation.”* (Regulation 883/2004 Art. 70.4). Thus, unlike other social security benefits, disability-related benefits are not exportable but bound to the state of residence.

However, this by no means excludes special non-contributory cash-benefits from the scope of Regulation 883/2004, but it even foresees access to these services when legally residing in another Member State. According to Vonk, unlike the exclusion of non-active citizens from the right to social assistance as foreseen in the Residence Directive 2004/38, which he views as a form of negative coordination, *“the co-ordination of special non-contributory benefits under Regulation 883/2004 constitutes a true form of co-ordination, because its sole purpose is not only to exclude exportability but also to guarantee access to these benefits in the host state”* (Vonk, 2020, p. 140 & 141). In other words, once a disabled person legally resides in another Member State, he or she is entitled to the disability benefits of that host state.¹⁵³ However, this does not

¹⁵³ The German implementation of this provision into the federal legislation on rehabilitation (SGB XI) illustrates this very well. According to this German social law, access to integration assistance services for foreigners residing in Germany requires an individual justification of the need to receive benefits (Art. 100 (1.1) SGB IX). This access is limited to those with either a permanent settlement permit or a temporary residence permit, with a high probability of residing permanently in Germany (Art 100 (1.2) SGB IX). While this could include, for instance, refugees

improve the possibility of disabled people moving to another member state in the first place.

So, is the case closed with the invention of the term 'special non-contributory benefits' until the political will is reached to expand the assumed rights following from the insurance principle to those unable to contribute to the insurance? When assessing the impact of Art. 140 & 141 on the national level, one can hardly come to that conclusion. As confirmed by a member of the Council's working group on this matter, the scope of 'special non-contributory cash benefits' is anything but homogeneous between the member states (expert 5). This results in significant legal uncertainty for the affected people. Depending on the national or regional system, the entitlements for disabled people, for example, may be fragmented¹⁵⁴. Thus, the question of which benefits fall under the special non-contributed cash benefits category may be difficult to answer.¹⁵⁵

In terms of clarity for disabled people, it is also not helpful that Annex 2 of Regulation 883/2004 lists several pages of additional exceptions for each member state. For example, while Italy and Sweden explicitly exclude disability allowances from being received abroad, Spain excludes "*schemes with the character of social assistance or a charity*" and its entire "*welfare system*". To make it even more obscure, Germany referred to its federal system, excluding benefits that were granted by its federal states not only from article 10 but from the scope of the entire regulation (Annex 2. III).

In contrast, regarding long-term care benefits, the principle of exportability is generally applicable. In line with the principle of single applicable legislation, the Regulation explicitly prohibits receiving cash benefits from more than one State. It is remarkable, however, that "*long-term care benefits in cash (...) must be treated as sickness benefits and are therefore provided by the Member State competent for cash benefits* (Art. 35). The Member State that provides the long-term care benefits may then invoice the country of origin.

(as the Social Court of Nuremberg has ruled it on March 15th, 2023), it may exclude members from other EU countries who cannot compete on the German job market.

¹⁵⁴ For example, as of 2020, the German Federal Participation Act („Bundesteilhabegesetz“) separates the entitlements for disabled people into care services, services of inclusion, and cash benefits for board and lodging.

¹⁵⁵ Part III demonstrates this difficulty for the Euroregion Meuse-Rhine

As if it were not already an administrative burden on people needing care, the regulation allows bi- or multipolar agreements between the member states (Art. 35 (3)). To address the administrative questions, including which cash benefits and services are covered, an administrative Commission was established, composed of government officials of each Member State.

Which conclusion can be drawn from the analysis of Regulation 883/2004 and amending Regulation 987/2009 on the coordination of social security systems in the EU, as well as from previous judgements by the ECJ? First, in terms of the above-mentioned questions regarding social coordination, the distinction between special non-contributory benefits and other forms of social security demonstrates that, in general, social security has been regarded as a cost rather than an investment. The result of this has been great legal uncertainty for disabled people regarding their mobility within the EU.

Secondly, because the pre-existing residence in the host state has been made a premise for falling under the scope of both regulations, Article 140 & 141 have fundamentally shifted the question of whether a person has access to a social security system to the question of whether that person has access to that Member State. For disabled people who do not participate in the first labour market, this can be a high threshold. It has been argued that shifting the discourse from no longer dealing primarily with the safeguarding of social security rights, but with residence rights (with the ultimate consequence of sending people back to their home country) has been a commonly used instrument on the international level to deal with social security rights.

Based on cases of the ECJ¹⁵⁶, the distinction between social assistance schemes and non-contributory benefits in EU social security law is becoming increasingly redundant (Carter, 2018; Vonk, 2020), before calling for the abandonment of the concept of non-contributory benefits and the introduction of a new category of minimum subsistence benefits, including social assistance schemes for economically non-active EU citizens. This new category should be based on a *“single, coherent principle that governs the relationship between*

¹⁵⁶ E.g. Case C-333/13 Dano vs. Jobcenter Leipzig, C-67-14 Alimanovic vs. Berlin Neukölln

benefit rights (Regulation 883/2004), on the one hand, and residence rights (Directive 2004/38), on the other.” (Vonk, 2020, p. 145)

To sum up, Regulation 883/2004 on the coordination of social security systems does not establish financial neutrality in the sense of a joint European social security scheme. Instead, it regulates the responsibility of who must provide social security and obligates the European member states to comply with their social security standards in cross-border situations. Remarkably, the Regulation establishes that citizens who fall under the scope of this regulation “*shall enjoy the same benefits and be subject to the same obligations under the legislation of any Member State as the nationals thereof*” (Art. 4). This is followed by explicitly including monetary social security benefits (Art. 7). Therefore, under EU law those who are eligible for cash benefits in the home country, are in principle also eligible to the same benefits when being abroad. Thus, the EU member states have been less protective about their social systems themselves, but instead showed concerns regarding the relationship between residence rights and access to their social systems.

With that in mind, the following sequence assesses whether the European Commission's most recent attempts to reform the rules for coordinating social security systems in Europe have addressed this relationship. The focus is on the Commission's proposal from 2016 for revising the regulation on social security coordination, with a view to the key attempts for change and the significant points of debate.

2.2.4 Attempts to coordinate income benefits related to disability

Before diving into the latest attempt by the European Commission to reform the coordination of social security systems, let us put the lessons learned from the previous analysis into a bigger context of the political willingness to reform the ESM and to give social security a greater significance in the European integration process.

First published in March 2016 as a preliminary version by the European Commission, the EU member states adopted the European Pillar of Social Rights (EPSR) in January 2017. While it is a legally non-binding document, the aim of the EPSR was to initiate far-reaching reforms of the European labour

markets as well as the social systems. While chapters one (equality and access to labour markets) and two (fair working conditions) were directly linked to labour, the third chapter addressed the issues of social protection and social inclusion. This chapter includes principle 17 addressing disability. Regarding the research question of whether disability can be a driving force from a charity-based to rights-based approach, the wording in the EPSR is remarkable: *“Disabled people have the right to income support that ensures living in dignity, (...)”* (EPSR, Chapter 3, Principle 17, p.21). Again, while the EPSR is legally non-binding by itself, it shows the political willingness of the member states to reform the ESM. The president of the European Commission at the time, Jean-Claude Juncker, even argued that *“In the Parliamentary history of Europe, never before have we seen so much progress made in social affairs”* (Rios, 2019).

It is undoubtedly true that the adoption of the EPSR opened a ‘window of opportunity’, considering that 24 out of 27 Commission legislative proposals connected with the European pillar of social rights were adopted into EU law in the following years. However, one of the remaining three proposals that have not been adopted concerned the revision of Regulation (EC) 883/2004 on the coordination of social security systems and the Regulation on its implementation (EC) No. 987/2009. When the European Commission published its first draft for a revised legislation in 2016, it recognized that the previous regulation had been outdated: *“It remains essential that the coordination rules keep pace with the evolving legal and societal context in which they operate by further facilitating the exercise of citizens' rights (...)”* (European Commission, 2016).¹⁵⁷

In its proposal, the Commission acknowledges the evolving legal aspect, particularly regarding the ECJ's rulings, and that the coordination of the social systems is deeply connected with solidarity. In the accompanying impact assessment¹⁵⁸, the Commission clarified that the added value of the new directive is that *“effective and efficient coordination needs to take account of changes in member states' national social security and social changes”* (EU

¹⁵⁷ COM (2016) 815 final

¹⁵⁸ SWD (2016) 461 final

Commission, 2016, p.3.). Therefore, unlike the Regulation of 2009, which was of purely administrative character to better implement the incentives of 2004, the new proposal of 2016 brought forward ideas to change these incentives and thus, to reform the existing rules on social policy coordination – including *“Removing special non-contributory cash benefits providing subsistence income from Regulation 883/2004”* (p. 4).

The Commission's draft regulation, complemented by several minor amendments, focused on five key areas:

- unemployment benefits,
- long-term care benefits,
- access to benefits for economically inactive persons,
- family benefits and applicable legislation for posted workers and
- persons working in two or more member states.

As for disabled people, the most significant changes have been proposed regarding long-term care benefits and access to benefits for economically inactive persons. However, the term 'disability' can only be found once in the entire draft, namely within the following definition:

“long-term care benefit” means any benefit in kind, cash, or a combination of both for persons who, over an extended period of time, on account of old-age, disability, illness or impairment, require considerable assistance from another person or persons to carry out essential daily activities, including to support their personal autonomy. This includes benefits granted to or for the person providing such assistance.” (Art.9)¹⁵⁹

It becomes clear that the Commission followed a purely medical understanding of disability when drafting this legislation, grouping it in the same subclause with age and illness. Interestingly, the provided definition separates disability from impairment, instead of viewing them as interdependent.

Nevertheless, the Commission's draft can also be regarded as an attempt to work towards a rights-based approach in social security, an idea that has been promoted long before. Some have recommended more than a decade earlier

¹⁵⁹ Draft regulation Art.9, amending Art. 1 (d), p. 26

that the changing patterns of work within Europe suggest the need for social policy in the EU to break from work-based entitlement to a citizenship entitlement (e.g. Offe, 2000, Abberley, 2002). However, until 2016 the *“European programmes put entry to the workforce at the core of their strategies to combat social exclusion”* (Abberley, 2002, p. 130).

Given that the Commission’s proposal has been proven to be so controversial, what have been the significant changes, and how would they have impacted disabled people’s possibilities to move abroad? Alongside some fine-tuning of (mostly technical) rules on administrative cooperation between the member states, the main changes proposed by the Commission would have covered the limits of application of the equal treatment principle for non-economically active EU citizens. This is particularly concerning the so-called special non-contributory cash benefits. To understand the Commission’s intent, it is worth having a look at the staff working document accompanying the proposal to amend Regulation 883/2004:

“For social benefits, the recent judgments in Cases C-140/12 Brey, C-133/13 Dano; and C-308/14 Commission v United Kingdom clarified that member states may choose to limit equal treatment for special non-contributory cash benefits and other social security benefits claimed by the economically inactive citizens to the extent permitted by the Free Movement Directive. This jurisprudence is not reflected in the Regulation, leading to a lack of transparency.” (Commission Staff Working Document SWD (2016) 460 and 461, p. 2).

Thus, the Commission acknowledges that the existing rules are insufficient to define under which conditions access to social security schemes may be denied. To solve this mismatch between the ECJ’s rulings and the outdated regulation, three solutions have been considered by the European Commission:

- Option 1: Allowing exceptions from the equal treatment principle regarding the coordination of social systems. These exceptions could either solely concern social assistance, a wider array of social benefits that are financed by taxes, or all special non-contributory cash benefits;

- Option 2: Removing special non-contributory cash benefits that provide subsistence income from the scope of Regulation 883/2004;
- Option 3: Improving communication without legislative changes.

While all three options have been considered when drafting the proposal, the Commission made clear that it preferred to add specific exceptions from the equal treatment principles as in option No. 1. (European Commission, 2016, p 4). That way, the regulation would foster transparency regarding social benefits for economically inactive EU citizens, *“including the extent to which member states’ social security institutions are permitted to limit the equal treatment principle for access to social benefits”* (ibid. p. 3).

While the Commission did not question the member states competence regarding granting access to social benefits, it emphasized that successful coordination requires a certain level of transparency. However, this attempt proved to be so politically sensitive that the EESC felt the need to *“stress that the existing rules are about coordination, not harmonisation of social security systems”* (EESC C 345/86, 2017, para. 3.5). At the same time, it becomes apparent that they could potentially affect the ESM directly.

Nevertheless, the EESC and the Committee of the Regions (CoR C 342/19, 2017, General comment No. 3) strongly supported the Commission’s proposal. Remarkably, the EESC explicitly pointed out that *“the new rules give citizens better protection in cross-border situations. The new rules are particularly relevant in view of [...] the promotion of greater independence and mobility for disabled persons, with an increasing number of citizens moving from one Member State to another needing long-term care benefits.”* Furthermore, both Committees urged the member states to clarify the conditions under which their citizens are entitled to export long-term care benefits when moving abroad, as well as the restrictions on social assistance by the host state. (EESC, 2017, para. 5.2 and para. 19).

Interestingly, neither the EESC nor the Committee of the Regions tried to downplay the political significance of the newly proposed legislation, but noted that *“the free movement of workers, being negative single market integration,*

has to be complemented by coordination of social security, which is positive integration" (CoR, 2017, General comment No 2). Instead, recognizing the political sensitivity of the topic, they tried to convince the member states that further integration regarding the consolidation of social systems, including non-contributory benefits, would be in the interest of the member states. Before the Commission's proposal has been forwarded to the European Parliament and the Council, the EESC urged the member states to *"also consider the advantages of receiving mobile citizens in general, even those who are inactive but, in one way or another, still contribute to the economy (and cultural diversity) of the host country"* (EESC, 2017, para. 1.8 and para. 5.9).

The political process between the European Parliament and the Council

Once forwarded to the European Parliament, the dossier has been brought to the EMPL Committee's agenda. The Committee's first step was to assign an independent study on the impacts that the Directive was likely to cause (see Giubboni a.o., 2017). The study assessed the functioning of coordination rules in areas targeted by the amendment proposal from the European Commission and evaluated the proposal's possible effects. Eventually, the researchers concluded that *"the Commission's proposal is intended to be, in terms of extension and coverage, one of the most ambitious reforms within the evolution of social security coordination law"* (ibid, p.9).

However, the study also highlighted a key aspect that became ground for intense discussion between the EU Parliament and the Council: some of the proposed changes could potentially impact fundamental principles of social security coordination and free movement law. Most remarkably, the researchers pointed out that *"the Commission [...] expressly derogates from the principle of equal treatment for economically inactive citizens moving from one Member State to another"*, adding that the Directive *"would in fact paradoxically exclude certain situations which are covered by current rules on sickness benefits, producing a loss of rights and entitlement and creating unwarranted obstacles to the free movement of persons within the EU."* (ibid., p. 10). In other words, the researchers largely disagreed with the previously published statements by the EESC and the CoR. Although the disclaimer pointed out that the expressed

opinions are not the Parliament's but solely the author's, it illustrates the Parliament's working ground.

Interestingly, regarding the freedom of movement of disabled people within the EU, the EMPL committee interpreted the directive relatively optimistically. In an opinion by the assigned rapporteur on the dossier in 2018, it was expressed that in her view, *“disabled persons should retain the portability of their social security rights and entitlements when moving from one Member State to another without discrimination. In this regard, the rapporteur takes note of the new chapter on long-term care benefits proposed by the Commission and welcomes the fact that disability benefits are now clearly covered by this chapter.”* (MEP Soledad Cabezón Ruiz, Rapporteur to the EMPL Committee, 2018).

This statement can be interpreted in many different ways: On the one hand, the rapporteur recognised that the topic of coordination of social systems strongly interacts with the possibility of disabled people moving abroad. Furthermore, she expressed her support for finding a European solution to this matter instead of solely leaving it to the member states. According to the Committee's opinion, this should also include a joint definition of disability and criteria for social security coordination. Thus, high hopes were put on the announced European Disability Card (see chapter 2.3.3). The Committee expected the Card to initiate a discussion on which benefits should be covered so that disabled people could enjoy their freedom of movement within the EU.

Regarding whether disability can be a driving force towards a rights-based approach in social policy, the EP's rapporteur explicitly pointed out the rights and entitlements of disabled people when moving to another member state.

On the other hand, however, the MEPs also welcome the approach of summarizing illness, long-term care, and disability in one chapter, clearly setting the tone for a medical understanding of disability. Furthermore, the proposed exceptions for economically inactive people from enjoying their right to freedom of movement have been recognized, but they have not been brought into the context of severely disabled people.

On the one hand, the EU Parliament's general support to reform the outdated social security regulation, the Council made clear that the *“social security systems in the EU are not harmonized. Every member state can decide who is insured under their legislation, what benefits they are entitled to, and what the conditions of access are.”* However, the Council also recognized that *“to ensure that the free movement of people is possible in practice, the national social security systems need to be coordinated.”* (Council Press Release of June 2, 2018).

Unlike the Parliament, the member states also expressed great concern over the new directive's financial impact. In an interview, a permanent representative at the Council reported that at first, the member states were unable to unanimously agree on four aspects of the proposal to revise the social security coordination (expert 5):

- General provisions, especially the applicability of the legislation
- Long-term care (including disability-related benefits)
- Family benefits, especially childcare
- Provisions regarding unemployment benefits.

In the following months and years, the Council and the Parliament worked on finding agreements on these topics. As for the chapter on long-term care, including disability-related benefits, the Council eventually proposed to set up an administrative body to specify the scope. Referring to the article in question (Art. 33 a. on long-term care benefits) the Council asked for a *“detailed list of long-term care benefits which meet the criteria [...] of this Regulation, specifying which are benefits in kind and which are benefits in cash and if the benefit is provided to the person in need of care or to the person providing such care.”* (Council File COD 2016/0397 § 15 a, p. 20). With this compromise, the member states eventually found an agreement that included the exportability of disability-related benefits (expert 5).

The most problematic issue, however, was the proposed chapter regarding unemployment benefits. The representative from the Council summarized that *“the Commission essentially proposed to switch the competence and switch the member states who is going to pay the benefits in case of frontier workers,”*

adding that “*there would have been some big winners and big losers.*” (expert 5). The proposed competence shift can be illustrated as such:

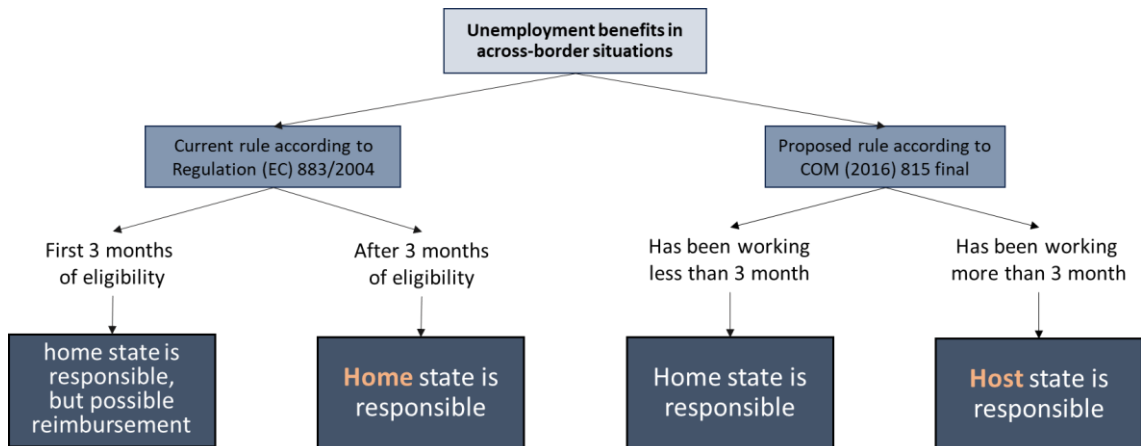


Figure 22: Competences for unemployment benefits in cross-border situations

The Commission’s proposal, therefore, implied not only a shift of competence, but it would also have made the duration of employment the relevant criterion for eligibility to unemployment benefits abroad. This would have disproportionately affected some member states, such as Luxembourg, where many workers live in the neighbouring countries due to lower living expenses. Additionally, there is a wide gap in performance between the welfare systems in different EU countries: While the best systems help reduce the risk of poverty by nearly 60 %, the least effective by less than 15 %, with the EU average being 35 %. This gap is part of the reason why some member states fear being the destination of ‘social tourism’, meaning a systematic immigration to profit from better social protection.

The difficulty in reaching an agreement over this issue within the Council may be explained by the different expectations towards social systems in general among the member states. In his comparative analysis of the national social security systems, van der Mei (2020) has identified a crucial difference: Some member states have chosen a risk-based system in which the amount of invalidity benefits does not depend on the duration of the respective insurance. Other member states, in contrast, chose an accrual system in which the benefit amount increases the longer someone has been insured before his/her

invalidity occurs (van der Mei, 2020). This makes the coordination between the systems difficult.

Due to these issues, the Commission's proposal caused three years of intense and highly politicised discourse over the European social system, both within the European Parliament and the Council. Eventually, despite the shared view that the 2004 Regulation needs to be reformed, no agreement over the Commission's proposal could be reached.

The interviewed expert for this issue, a political advisor to the EP's rapporteur on social security coordination, reported that within the European Parliament, there has been consensus on a majority of issues (expert 4). However, there were three open issues between the Parliament and the Council: First, notification procedures within the framework of social security for the posting of workers. The second, less controversial issue concerns multi-activity. The third, however, has been very sensitive: the payment of unemployment benefits. The difficulty lies in the fact that different majorities exist in both institutions in various areas, complicating the search for compromises (expert 4). Eventually, on April 19th, 2019, the EU Parliament voted with a narrow margin in favour of postponing the issue to the next parliamentary period, which was to be elected a month later.¹⁶⁰

2.3 The autonomy dimension: Access to assistance services

“For many persons with disabilities, support represents an essential precondition for their active and meaningful participation in society, while preserving their dignity, autonomy and independence” (Gerard Quinn, UN Special Rapporteur on Disability, 2017, p.5)

The third and final dimension of Active European Citizenship to be addressed in this thesis is the ability of severely disabled Europeans to live an independent

¹⁶⁰ 291 votes in favour of postponing the issue, 284 against it and 6 abstentions.

life in cross-border situations. As the UN Special Rapporteur on Disability at the time has pointed out in 2017, for many disabled persons, preserving their autonomy means having access to adequate assistance services. However, when transferring the autonomy dimension to the sub-category of access to assistance services, one might sense a contradiction: Obviously, needing assistance services constitutes a certain dependency on others by itself. However, this argument may likewise be applied to all kinds of services essential to modern life. Everyone, regardless of disability, is dependent on water supply, financial services, health care, public order, or other services. Full autonomy from others is thus neither an aspiration nor desirable from the point of view of European society as a whole. Instead, the autonomy dimension is understood as the ability to make self-determined decisions (and deal with the consequences of these decisions) by receiving assistance services when needed.¹⁶¹

That said, the question of whether disabled people have access to personal assistance services in cross-border situations can be negated in most cases. The question of how the dependency on assistance services may prevent disabled people from moving and residing abroad, thus does not require any clarification. Instead, this chapter's analysis follows the question of why access to personal assistance services falls far behind in the process of EU integration.

The analysis starts with decoding the thinking behind the legal sphere in which social services in general and assistance services for disabled people in particular are provided in the EU. Given that there are already a variety of European regulations for social services in cross-border situations, such as healthcare or childcare, the subsequent question is how existing legal provisions are to be interpreted regarding the medical versus the social model of disability. Once the key contentious issues regarding personal assistance have been identified, the analysis continues by asking whether significant changes in the approach of disability-related EU legislation can be observed.

¹⁶¹ This approach stands in sharp opposition to the reality in institutionalized settings for disabled people, where workflows and professionalized processes dictate the daily routine of the inhabitants. The European Disability Forum as well as MEPs within the Permanent Intergroup on Disability in the European Parliament are calling for deinstitutionalising disability policies. However, this topic falls outside this thesis' scope.

The chapter concludes with an analysis of two recent attempts to reform access to these services: the EU Framework on Social Services for disabled people and the introduction of a European Disability Card.

Quality differences can be an additional barrier to moving abroad

Regarding personal assistance services to ensure a person's autonomy, the five aforementioned aspects of accessibility may be complemented by a sixth: The quality dimension. If a person needs personal assistance to cope with everyday situations, the aforementioned accessibility criteria may be insufficient. It is likewise important that these services match the person's needs in terms of quality. While physical accessibility is defined by quality criteria such as usability and safety, several interview partners have pointed out that the significant differences in quality of services can be a real barrier to moving abroad, some of whom provided concrete examples (experts 6,7, 10, and 12).

The following hypothetical example illustrates how problematic this barrier can be: A physically impaired person in the Netherlands might need assistance to maintain personal hygiene. The Dutch local authority concluded, on the grounds of a personal assessment, the need to assist daily with showering, getting dressed, and toilet visits. This process might take up to one hour every morning. The person gets a job offer from a German university that requires on-site presence due to teaching. The German authorities recognize the disability status and grant access to disability-related assistance services. However, according to the authority's assessment, assistance with visiting the toilet is not a disability-related aid, but a care service to be provided by an ambulatory nursing service and financed by a nursing care insurance. The person is now in the situation not only to apply for disability-related assistance at the local authorities, but also to organise a nursing service and prove to the nursing care insurance his/her eligibility – which might not be possible prior to arrival because the university' is inability to provide an employment contract without a German residence address. Thus, until the local authority has completed the

process of granting both disability-related assistance and care services, the person is left alone with toilet visits.¹⁶²

In other words, even though the European Disability Card will, at least in theory, ensure that disability status is recognised in cross-border situations, not only access to assistance services needs to be ensured, but the scope and quality of such services must be on an equal level as in the state of origin to meet the person's demand. As illustrated in the example, this is not excessive demand but can be a significant barrier to free movement for those affected.

The reality, however, looks very different. In 2020, the European Network on Independent Living (ENIL), a platform for disabled people across Europe, conducted a survey in 43 countries regarding access to personal assistance. The survey included 143 disabled people who were experts on the topic to rate access to these services in the country. Even though the survey focused not on cross-border situations but on access to assistance services in general, the response evaluation is alarming: Except for Slovenia, access to personal assistance services in all EU member states has been rated 'insufficient' or 'requiring improvement'. 8 of the 43 countries included in the survey had no publicly funded personal assistance scheme (ENIL, 2022, p.24). Other countries have avoided establishing the right to personal assistance in national law. In Ireland, for example, personal assistance has been granted in the course of a 'pilot project' for more than 28 years, and in Croatia for over 10 years (ENIL, 2022, p. 26). Even in member states where the authorities have established a legal framework, this alone does not ensure that disabled people have access to assistance services. In Belgium, the survey's respondents reported a waiting list of up to 23 years for access to the personal budget required to reimburse personal assistance by the responsible authority. That is *after* the 'applicants' have gone through an assessment process to prove their eligibility. This process can be humiliating at times, because to be granted access to the waiting list for personal assistance, the applicant is responsible for 'proving' that

¹⁶² This example is hypothetical, but not unrealistic. In Germany these services are labelled either as "care services" according to SGB XI or "services for rehabilitation" according to SGB IX. The allocation differs between the German federal states and depends on the personal assessment. The outcome has significant impact not only on the recipient, but also on the provision of that particular personal assistance service.

he/she cannot live independently without assistance. Even if a legal framework for personal assistance exists and the person is granted, the survey revealed a significant quality lack: 88 % of the survey respondents stated that the funding for personal assistance did not cover all their needs in practice (p.32).

When asked about the potential reasons for this insufficient coverage of personal assistance services, the interviewed expert from ENIL responded that most governments are simply reluctant to grant sufficient financial resources (expert 10). In that respect, it is not surprising that the authorities are even more reluctant to grant disabled people from other EU countries access to these services. According to the survey, only 14 of the 43 countries allow access to personal assistance irrespective of citizenship. Regarding residence status, the number of countries that permit access is even lower: Only eight countries permit foreign nationals to reside in their territory. As the authors of the survey point out, *“This is particularly problematic for countries belonging to the EU. [...] Disabled people in need of personal assistance who want to leave their country of origin and work in another member state, do not enjoy the same privilege, since they cannot get access to the host countries’ personal assistance scheme without, in some cases, receiving citizenship first.”* (ENIL, 2022, p. 37) In that regard, access to personal assistance services is an even bigger barrier to residing abroad than access to social security schemes.

When asked about this problem, a high-ranking official from the European Commission referred to a flagship initiative to improve the quality of social services for disabled people (expert 1). It is therefore worth looking at the Commission’s plans in this respect.

The flagship initiative to improve the quality of social services has been announced in the Strategy for the Rights of Persons with Disabilities 2021-2030. The Commission promised that *“building on the existing voluntary European Quality Framework for Social Services, the Commission will present, by 2024, a specific framework for Social Services of Excellence for persons with disabilities, to improve service delivery for persons with disabilities [...]”* (Strategy for the Rights of Persons with Disabilities 2021-2030, p. 9).

That is remarkable by itself: On the one hand, the flagship initiative can be seen as an attempt to go beyond the mainstreaming of policies towards a disability-specific framework. On the other hand, the Commission supports providing disability-related services at the local level, recognizing that its competences are limited to working on a 'voluntary framework, even though, as has been illustrated, there is a clear barrier to the free movement of EU citizens.

The European Association of Service Providers for Persons with Disabilities (EASPD), representing roughly 20.000 service providers across the EU, has published its 'first reflection' on the Commission's attempt (EASPD, 2022). According to the EASPD, services, including personal assistance, face significant challenges. Quality aspects include outdated infrastructure, staff shortages, poor working conditions, and a sector often offering unattractive work opportunities. The COVID-19 pandemic has worsened this situation.

In its statement, the organization criticizes the lack of a common European definition of quality, non-coherent policy frameworks, and a lack of funding opportunities. Pointing out that "*the lack of a common understanding of quality services can hinder the development and improvement of services in the member states*" (EASPD, 2022, p. 4), it demands a set of common quality principles for SSGI. A key aspect in this respect is improving the attractiveness of jobs in this area to counter the labour shortage of service providers.

How does this answer the chapter's guiding question of why access to personal assistance services falls far behind in the process of EU integration? Regarding the quality aspect of accessibility, there are two answers: First, despite having an impact on disabled people's ability to move and reside abroad, the EU Commission has limited its "flagship initiative" to expanding the already existing and voluntary European Quality Framework for Social Services. The second answer to this question is that the cross-border aspect, regarding quality of services, is of very low priority among stakeholders. Considering the devastating feedback that the European Court of Auditors received for its special report regarding access to support services in general, it is not surprising that even the main lobby organization of service providers, EASPD, does not raise this topic.

2.3.1 The various dimensions of accessibility to assistance services

Legal uncertainty regarding access to assistance services in cross-border situations thus starts with the already problematic terminology of social services and SSGIs. However, as has been pointed out, the outdated terminology is not only problematic from a legal point of view but also from expectations regarding quality, purpose, and supplier-customer relationships (e.g. Bauby, 2013). For that sake, the following analysis aims to set out the integration process of SSGI and the consequences for recipients of assistance services.

The basis for the discussion is the so-called 'service directive'¹⁶³. The directive entered into force in 2006, the same year as the Commission's Communication document on SSGI. Its purpose was to establish general provisions on providing services across internal EU borders and on the free movement of service providers. It aims to simplify administrative procedures, improve service providers' access to information, and, importantly, define the criteria under which access to a service market may be denied.

The service directive is a clear marker for the intermediate status on the way towards a 'social Europe' (e.g. van den Gronden, 2013). Furthermore, it visualises the different speeds at which the creation of the European common market is fostered in the social sector compared to other service sectors (see e.g. Martinsen, 2013; Bauby, 2013). This conclusion is made on the ground that while the Directive aims to remove barriers to trade in services by simplifying administrative procedures, enhancing consumer rights and fostering cooperation between the member states, SSGI has been carefully detached from the Directive's scope altogether. Specifically, it excludes "*healthcare services (...) regardless of the ways in which they are organised and financed at national level*" (Art. 2 f.) as well as "*social services relating to (...) persons permanently or temporarily in need which are provided by the State, by providers mandated by the State or by charities recognised as such by the State*" (Art. 2 j.). Thus, the previous classification of care under healthcare or social services does come into effect in this context. Additionally, the Directive's

¹⁶³ Directive 2006/123/EC on services in the internal market of December 12th, 2006

subject matter makes it very clear that “*this Directive does not affect the social security legislation of the member states*”. (Art. 1.6)

While the exclusion of social services from the scope of the directive is less surprising, it is remarkable that the Directive offers a reasoning for why (in the case of SSGI) member states' national law outweighs Community law. These reasons include public health as well as “*preserving the financial equilibrium of the social security system*” (Art. 4.8). Therefore, although establishing a common market for services is a key competence of the EU, legislative acts on the provision of services may cause a spill-over effect and thus an indirect effect on SSGI (see also Tryfonidou, 2013).

Since the directive has not been revised since 2006 and leaves little room for interpretation and leeway, from a legal point of view, the analysis seems short and clear. Yet, recalling the aim of this chapter, the analysis follows the question of whether there has been progress in thinking since the directive entered into force.

First and foremost, a key development has been that the EU and its member states have signed and ratified the UNCRPD, which entered into force in 2011, five years after the service directive. In ratifying the Convention, the EU has committed itself, among other aspects, to “*take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to (...) services open or provided to the public (...)*” (UNCRPD, Art. 9). Thus, not only does the UNCRPD directly address the issue of access to public services, but it also highlights the mainstreaming approach when drafting new legislation that affects public services.

Secondly, there are more aspects to be considered regarding the accessibility of assistance services for disabled people than the sole financial aspect of who reimburses the service providers. Article 9 of the UNCRPD draws upon various aspects of accessibility, which may be summarized as such:

Dimension of accessibility of assistance services	Description
Social / Attitudinal Accessibility	Removal of prejudices and negative biases towards disabled people.
Economic Accessibility or Affordability	Access to (public) financial resources to reimburse providers of assistance services, and the costs connected with receiving public financial aid.
Physical Accessibility	Availability of services and the service quality in terms of usability and safety.
Information Accessibility	Refers to the content of available information. This entails, for example, not only general information available about facilities, goods, and services but also information regarding disposability.
Communication Accessibility	Refers to the format of available information and whether there are alternative communication modes, such as sign language for deaf persons.

Figure 23: dimensions of accessibility of services as defined in the UNCRPD

Following the UNCRPD, the accessibility principle has found its way into EU documents. As such, the provisions included within the European Pillar of Social Rights (EPSR) in 2017 should be understood as a memorandum of intent, rather than a legal basis. Nevertheless, while referring to the UNCRPD, the member states stated that “disabled people have the right to [...] services that enable them to participate in the labour market and in society [...]”¹⁶⁴. However, whether this includes an EU-wide labour market and a European society is not specified.

Charitakis (2020) has analysed the implementation of the principle of accessibility, as stated in the UNCRPD and the EPRS, in the context of goods and services. Referring to the different aspects of accessibility defined by the UNCRPD and implemented in the EAA, Charitakis has pointed out that accessibility has been enshrined as a fundamental principle in the UNCRPD (Art. 9), aiming at identifying and eliminating barriers that prevent inclusion.

¹⁶⁴ Principle 17 of the European Pillar of Social Rights

Therefore, the convention “*embodies the social-contextual model of disability*” (Charitakis, 2020, p. 222). Drawing upon the above-mentioned dimension of accessibility to services, he concluded that while there are differences in the magnitude of EU actions, there are examples to be found in all these aspects. However, he also concluded that the EU’s attempts to foster accessibility follow a mainstreaming approach, meaning that accessibility is considered a precondition when drafting an otherwise unrelated piece of legislation. While European disability organisations widely support this approach (experts 7, 8, and 10), it is insufficient to deal with the accessibility of assistance services for disabled people in cross-border situations. To address this issue, a disability-specific legislative act appears to be necessary. Adopting the so-called ‘European Accessibility Act’ (EAA)¹⁶⁵ in 2019 proved that disability-specific legislation can be drafted at the EU level.

The EAA aims to improve the internal market for those products and services the EU Commission identified as most relevant for disabled people, particularly in communication, passenger transport and finance¹⁶⁶. However, it does not include SSGI, such as assistance services. Nevertheless, although the EAA does not directly contribute to this chapter’s underlying issue of disabled people’s access to assistance services, it does contribute to whether any developments can be observed.

First, in the legislative process leading up to the EAA, the Commission highlighted that despite the UNCRPD laying out the aspects of accessibility, “*current national accessibility requirements relating to specific products and services differ from Member State to Member State, and sometimes within a Member State*” (EU Commission Staff Working Document, 2015, p.3), adding that this divergence in national legislation is likely to increase. The Commission saw a market risk in this fragmentation of accessibility and even quantified this risk in numbers: According to the impact assessment, different national regulations on accessibility would add up to a total annual cost of approximately 20 billion Euros (ibid., p. 6). Instead, the Commission proposed several options,

¹⁶⁵ Directive (EU) 2019/882

¹⁶⁶ The products and services covered by the EDA include computers, ATMs, smartphones, TV and other audio-visual media, phone services, services related to passenger transport, banking services, e-commerce and e-books.

of which the most far-reaching was an “*EU Directive defining common accessibility requirements*”¹⁶⁷. This option was expected to cut the costs of the status quo in half. Eventually, this option was adopted in 2019. Thus, even though the aim is to decrease market barriers rather than to improve freedom of movement of persons, the alignment of the criteria for accessibility on the EU level shows a significant development towards European integration in disability policy since 2006.

Secondly, the EAA demonstrates not only that disability-specific legislation is possible at the EU level, but it also shows how the Commission’s interpretation of mainstreaming. Instead of supplementing legislation with disability-related aspects, the disability-specific EAA defines accessibility as a precondition for any legislation within the directive’s scope. Not only is this a significant development in itself, but it also prepares the path for further harmonising disability-related policies in the EU:

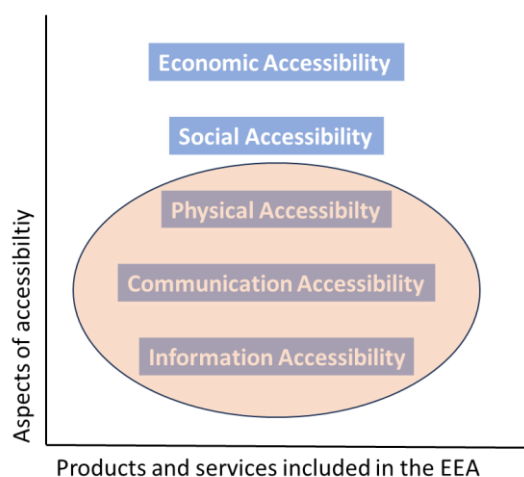


Figure 24: Scope of the European Accessibility Act¹⁶⁸

Until now, the EU has defined criteria in terms of physical accessibility, information accessibility and communication accessibility. Recalling the UNCRPD’s definition, neither social nor economic accessibility is included. However, the EAA may cause a spill-over effect on these areas. The extension of the EAA’s scope may take place in two ways: First, in its current form, the EAA is limited to a small number of specific products and services. The scope

¹⁶⁷ Ibid. p. 5

¹⁶⁸ Own depiction

can be extended to further products (some of which might be developed in the future) or even to entire economic sectors. This would mean a horizontal expansion of the EAA alongside the x-axis in Figure 21.

The second option is expanding the EAA's definition of 'accessibility'. In its current form, the EAA refers to accessibility in terms of information, communication, and physical accessibility. There are no provisions regarding the economic and social accessibility of products and services. However, these two aspects are included within the UNCRPD and, therefore, must be recognised by the EU. A vertical extension (alongside the y-axis of Figure 21) of the EAA to include these aspects appears to be a realistic scenario for further integration.

2.3.2 The assumed dependency of assistance services receivers

In a public consultation by the European Commission prior to the EU disability rights Agenda 2021-2030, many stakeholders criticized the legal uncertainty regarding access to social services. At best, this is a massive understatement, starting with confusion about the terminology 'social service' used by the public, stakeholders, and even policy makers and authorities, including the European Commission.

A short digression into economics is needed to understand the European way of thinking regarding the nature of various services. EU law highlights Services of General Interest (SGI) within the services sector. This is a comparatively vague concept that does not necessarily comply with the national legislation of the member states. Very broadly, these services are deemed indispensable by society because everyone depends on them. This includes, for instance, energy and water supply, health services, education, and many others. They differ from other services that are dispensable from the point of view of society as a whole, such as specified consultancy services or car repair services, etc. Because SGI greatly depend on the financial and regulatory involvement of public authorities, the economic sector of SGI is subject to many political and legal debates. At the core of these debates is often the underlying question of whether public support is truly needed to obtain that service, or whether it is dispensable whenever the service cannot be economically sustainable. Those who depend on disability-

related assistance services find themselves in this area of tension. In other words, access to assistance services for disabled people (as with most social services) depends heavily on whether these services are deemed indispensable SGI by the society providing these services.

However, this alone is insufficient to draw a line on the accessibility to services. SGI are again being differentiated into two categories by EU law: Services of General Economic Interest (SGEI) and Non-Economic Services of General Interest (NESGI). The key difference is that the first is provided against some form of financial payment, while the other is not. This differentiation is crucial for assistance services for disabled people. SGEI are regulated by EU law¹⁶⁹, for instance, in terms of quality, affordability, or equal treatment. Thus, if a service is classified as SGEI, EU law ensures a certain degree of protection of consumer rights, including accessibility and the needs of vulnerable groups such as disabled people (Neergaard, 2013). NESGI, in contrast, are not regulated and therefore decisions regarding the scope and the access to that service are solely within the competence of the member states.

To achieve legal clarity in cross-border situations, a transparent allocation of disability-related assistance services to either one of these categories would be key. However, two problems are connected: First, even though the access right to SGEI has been established with the EU Charter of Fundamental Rights (Art. 36), neither the Charter nor the EU Treaties provide a sufficient definition of what classifies as an SGEI. This results in a lack of homogeneity between the member states. For disability-related assistance services, the broad categorisation along some form of economic activity is insufficient. First, whether or not there is a payment depends on the respective service. The provision of a wheelchair, for instance, may not be subject to a payment, while accompanied grocery shopping may require a fee. Second, there are significant differences between the member states: In Germany, disabled people are granted a budget according to their degree of disability, from which assisting

¹⁶⁹ Protocol to the Lisbon Treaty No. 26, Article 1, referring to Art. 14 TFEU and Art. 106 (2) TFEU

services can be purchased. Thus, there is a clear economic component.¹⁷⁰ In Denmark, in contrast, disability-related services are tax-funded and provided by the state. A payment from the recipient of the assistance services does not take place. In an interview conducted for this thesis, the Vice-Chair of the Disabled People's Organisation Denmark (DPOD) and EESC member (expert 6) reported that even the supply of her wheelchair is classified as a NESGI. This has the effect that, according to Danish law, she loses the entitlement to her wheelchair if she stays abroad longer than 30 days, effectively causing a considerable burden on her ability to move and reside abroad.

To further complicate the access to assistance services, one more term has to be introduced: 'Social Services of General Interest' (SSGI). Unlike the previously outlined terminology, SSGI is neither a legal term in EU law nor commonly used in the member states (Neergard, 2013). However, while the term itself is absent from EU treaties or secondary law, SSGI can be found in other EU documents, such as policy documents by the Commission (see e.g. Freire, 2014, p. 29). Most notably, the European Commission has laid out its understanding of SSGI in a Communication document on implementing the Lisbon programme.

*"What do we mean by social services in the European Union? In addition to health services, (...), we find two main categories of social services: statutory and complementary social security schemes, organised in various ways (mutual or occupational organisations), covering the main risks of life, such as those linked to health, ageing, occupational accidents, unemployment, retirement, and disability; other essential services provided directly to the person. (...). These services include activities to integrate persons with long-term health or disability problems."*¹⁷¹

Thus, according to the EU Commission, SSGI generally aim to ensure the fundamental human rights of the most vulnerable, including disabled people, by implementing services according to their individual needs. It may be argued that

¹⁷⁰ The term 'social economy' is widely used in Germany. Within this eco-system disability-related services are granted according to the so-called Sozialgesetzbuch IX (SGB IX).

¹⁷¹ [Communication COM \(2006\) 177 final](#). Implementing the Community Lisbon programme: Social Services of General Interest in the EU. Brussels, April 26th, 2006, p. 4

SSGI are reflecting basic social rights and lay the basis for public social infrastructure, including hospitals, care homes, schools as well as services for disabled people among others. Traditionally, in Europe, these services have been closely linked to the national social welfare systems. Furthermore, SSGI are distinguished from other services in being personalized so that the individual needs can be met.

To distinguish social services from other SGI, the EU Commission has defined certain characteristics, especially regarding the ecosystem in which the services are provided. This includes a solidarity-based financing system, a non-profit provision of these services as well as “*an asymmetric relationship between providers and beneficiaries that cannot be assimilated with a ‘normal’ supplier/consumer relationship*” (ibid. p.5).

To sum up, services of general interest in the EU are categorized as the following:

Services of General Interest (SGI)	
<i>Services of General Economic Interest (SGEI)</i>	<i>Non-Economic Services of General Interest (NESGI)</i>
<ul style="list-style-type: none"> • Recognizing the essential role of national, regional, and local authorities in providing, commissioning and organising SGEI. • Linking SGEI as closely as possible to the needs of the users. • Recognizing geographical, social, or cultural differences between various SGEI and between the needs and preferences of users. • High level of quality, safety, and affordability of SGEI. • Guaranteeing user rights, equal treatment, and universal access. 	<ul style="list-style-type: none"> • Not covered by EU primary or secondary law. • Provisions of the Treaties do not affect the competence of member states to provide, commission and organise NESGI.
<i>Social Services of General Interest (SSGI)</i>	
<ul style="list-style-type: none"> • Can be of economic (SGEI) or non-economic (NESGI) nature. • Include Health services, Statutory and complementary social security and other essential services provided directly to the person. • Respond to the needs of vulnerable citizens, including disabled people. • Based on the principle of solidarity. • Service is personalized according to the individual's needs. • Relationship between service provider and recipient is asymmetric and cannot be compared to a regular supplier/consumer relationship. • They are rooted in local and cultural traditions due to the geographical proximity of the service provider and its recipient. • The service is not for profit. • Providing the service includes the participation of voluntary workers. 	

Figure 25: Definition of Services of General Interest (SGI)

The European Association of Service Providers for Persons with Disabilities (EASPD), an umbrella organization of service providers located in Brussels, has rightly pointed out that assistance services for disabled people are developed on the basis of social inclusion and the principle of solidarity and equal access. *“In that sense, they represent a type of Social Services of General Interest (SSGI), which encompass services provided directly to the person”*. (EASPD, 2022, p. 2). Yet, how does the breaking down the different types of Services of General Interest and the allocation of assistance services for disabled people help to understand the circumstances under which disabled people may receive these services abroad?

There are several conclusions to be drawn: First and foremost, under Primary law the European Commission is bound to the principle of subsidiarity in areas which do not fall under the exclusive competence of the EU, meaning that the EU *“shall act only if the objectives of the proposed action cannot be sufficiently achieved by the member states (...)”*¹⁷². However, because SSGI can neither be allocated to SGEI nor NESGI, the assumption that the provision of assistance services lies solely within the competence of the member states must be negated (Neergaard, 2013). Neither are they explicitly within the scope of EU regulation. Thus, unlike the previously mentioned policy fields of anti-discrimination and social security, access to assistance services is somewhat of a grey area.

For those who depend on these services, this is, of course, problematic for numerous reasons. The lack of a transparent allocation of SSGI to either SGEI or NESGI results in an even greater lack of legal clarity regarding the access entitlement. Instead, there is no legal basis for SSGI other than the aforementioned communication by the European Commission of 2006. This communication appears to be outdated both in its wording and in its essence. Especially the wording *“persons with long-term health or disability **problems**”* (EU Commission, 2006, p.4)¹⁷³ not only shows the person-centred, medical understanding of disability, but at the same time, the assessment of disability as a negative feature of that person. This contrasts with a modern, social

¹⁷² Art. 5 (3) TEU)

¹⁷³ Communication COM (2006) 177 final

understanding that views disability as the interaction of physical impairments in an inaccessible, external environment. Just as outdated appears the EU Commission's differentiation between an "*asymmetric relationship between providers and beneficiaries*" of SSGI on the one hand and a "*normal supplier/consumer relationship*" of non-SSGI service recipients on the other. (ibid., p. 5). This corresponds to the idea of 'caring' for disabled people, justifying unequal treatment and a dependency on service providers. Disability scholars have criticized these dependencies since the 1980s (e.g. Oliver, 1983).

Finally, the definition of SSGI must be questioned regarding the features of being non-profit oriented and the necessity of involving voluntary workers for two reasons: First, disabled people are categorized by the European Commission as a "*vulnerable group*" (EU Commission¹⁷⁴, 2013, p. 63). However, "*the categorization of public services related to disability as services for persons belonging to a 'vulnerable group', (...) does not appear consistent with the values of the UN Convention, which portrays persons with disabilities as rights-holders on an equal basis with other members of society*" (López, 2020, p. 291).

Second, since the Commission's document in 2006, assistance services for disabled people have increasingly been professionalised. A key driver for this change has been the (EU ratified) UNCRPD, which established the right of self-determination. As for providing assistance services, this self-determination requires a choice between at least two service providers and the abandonment of support service monopolies. This has been translated into national law in most member states, for example, by the German 'Bundesteilhabegesetz' of 2017. Essentially, implementing the right to choose the service provider has created a social economy, similar to those already existing in other social policy fields such as health or care services for the elderly. Not only are many of the operators in this field profit-oriented, but there are also first attempts by investors to invest in this field.¹⁷⁵ To conclude, the current classification of Services of General Interest leaves the recipients of disability-related assistance

¹⁷⁴ Commission Staff Working Guide SWD (2013) 53 final

¹⁷⁵ Examples are for instance the 'Haus Weitblick', a living facility for disabled people with severe intellectual impairments in Rosdorf, Lower Saxony or a centrum for disabled people with mental impairments in Glückstadt, Schleswig-Holstein.

services in great legal uncertainty. Furthermore, the definition of SSGI that the EU institutions have used until today must be regarded as outdated and, therefore, unsuitable for regulating access to assistance services for disabled people (van den Gronden, 2013).

These conclusions are not simply based on analysing abstract wordings in outdated EU documents with limited significance. Instead, the outdated EU legislation has very real consequences. In 2015, a legal dispute between the EU Commission and the Slovak government culminated before the ECJ in a case concerning the exportability of personal assistance services for disabled people¹⁷⁶.

The Commission claimed that Slovak national law failed to grant beneficiaries residing in a Member State other than the Slovak Republic, such as care allowance, assistance allowance, and a compensatory allowance for increased costs to compensate for severe disability. The Commission argued that these benefits should be exportable, referring to primary and secondary EU law.¹⁷⁷ Essentially, the Commission views the Slovak authorities as responsible for reimbursing non-monetary assistance services for their disabled citizens in cross-border situations.

However, the Slovak government differentiated between personal assistance services and other SSGIs in its legal counterargument. According to the Slovak government, there is a significant difference between services to improve their state of health and benefits with the purpose of integrating disabled persons into society. Unlike health services, which are exportable¹⁷⁸, the Slovak government argued that individual assistance services for disabled people would not fall under the scope of EU legislation. This is where the legal trouble started: Slovenian assistance services, including personal assistance, are only granted after individual medical *and* social examinations. Therefore, the EU classification along the line of medical necessity fails.

¹⁷⁶ ECJ Case C-433/13 'European Commission vs. Republic of Slovakia'

¹⁷⁷ The Commission specifically referred to Article 48 TFEU and articles 7 and 21 of Regulation (EC) No 883/2004 on the coordination of social security systems (see Chapter □2.2.2)

¹⁷⁸ Health services are generally exportable according to Regulation No 883/2004 (Art. 3(5))

In its judgment, the ECJ has avoided elaborating on this issue. Instead, the Court used another line of classification: whether the respective service is personalized according to the individual's needs and provided to the person. In other words, the question is whether the respective service qualifies as an SSGI as previously described, or a benefit is granted without personal assessment on a generally applicable basis. (ECJ Case C-433/13, paragraph 71 & 72). In the case of Slovakia, *"the objective pursued by the Slovak legislation is to grant severely disabled persons the benefit which is the most appropriate to their personal need"* (ibid., paragraph 78). That means these benefits do not fall under the scope of EU regulation, particularly Regulation No 883/2004, and are therefore not exportable.

From a legal point of view, the ECJ's argument is comprehensible. However, from a rather sociological point of view, the ECJ's reasoning is questionable as to why the Slovak society aims to include disabled people in society by utilizing personal assistance. As previously elaborated, *"from a rights-based perspective, disability does not intrinsically render a person vulnerable; rather, it is the lack of access, information and support which intensifies vulnerability."* (López, 2020, p. 291). Thus, the individual assessment of a person's need for personal assistance aims at guaranteeing the quality of this support to enable them to participate in society. The fact that Slovak law takes the social component into the assessment shows the social responsibility to do so. In the mentioned legal case, in contrast, the ECJ argues that because the assistance services are granted on an individual basis, the recipient is not entitled to receive these services in cross-border situations.

In other words, if the Slovak national legislation were designed less efficiently, for example, generally financing a certain number of hours for personal assistance per week according to a scale of 'degree of disability', this would fall under EU legislation. Thus, the principle of organising services according to individual needs, as foreseen in the UNCRPD and thereafter in the EU's strategy on the rights of persons with disabilities 2021-2030, is turned against disabled people, to their disadvantage.

2.3.3 Mutual recognition of disability: The European Disability Card

One of the key developments concerning the autonomy dimension is the introduction of a 'European Disability Card', a second flagship initiative of the Disability Rights Agenda 2021-2030. The initiative was built upon a pilot project that included eight EU countries¹⁷⁹. Essentially, this card aims to ensure that foreign EU citizens with disabilities can access the same special conditions and preferential treatments as nationals when temporarily visiting another EU country. That said, the limitation is already enshrined in this objective, as the card's scope is limited to *temporary* visits. Thus, it is not aimed at easing permanent residence.

Nevertheless, the analysis of the policy-making process of this piece of legislation is revealing in several aspects:

- Where do policymakers identify the problem, and what is the approach to foster cross-border activities for disabled people?
- Who is (not) supporting initiatives to shift competences in disability policy from national to EU level, and where were the red lines in the negotiations?
- How does the European Disability Card influence the European integration of policies that affect access to assistance services abroad?
- What are the limits of the Card, and could their introduction lead to easing permanent residence in the future?

To start with the first question, the European Disability Rights Agenda points to difficulties regarding access to services arising from the different approaches to disability: *"When moving to another Member State for work, studies, or other reasons, persons with disabilities may experience difficulties to have their disability status recognised. This means that they may face barriers to access services, including [...] benefits for persons with disabilities in that country."* (European Disability Rights Agenda 2021-2030, p.6)¹⁸⁰.

Recognizing that disabled persons should enjoy equal rights, the agenda promises that *"the Commission will work with member states to expand the scope of the mutual recognition of disability status [...]"* (ibid.) The disability

¹⁷⁹ Belgium, Cyprus, Estonia, Finland, Italy, Malta, Romania, and Slovenia

¹⁸⁰ Section 3.1. "Moving and Residing Freely"

card, therefore, aims not only at addressing the issue of access to services but also at disability-related benefits in the host state.

It is fair to note that non-legally binding documents such as the EU disability strategy alone cannot be the scale to measure political intention in a policy field primarily within the member states' competence. It is even more striking that in the run-up to the European Disability Card, the Council agreed on the following:

“Due to the lack of mutual recognition of disability status between member states, persons with disabilities often face specific and significant difficulties and barriers when exercising their fundamental rights of equal treatment, non-discrimination, and free movement.” Council of the European Union, 2024, p.7)¹⁸¹

In their analysis of the impact of the European Disability Card, the member states acknowledged that disabled people are, in fact, limited in enjoying their right to free movement while pointing out the problems arising from different approaches to disability. That by itself is a significant development.

Furthermore, during the legislative process leading to the European Disability Card, it can be observed that the initial proposal by the European Commission has not been downgraded but has even been expanded in its scope. Due to significant lobby activities by stakeholders such as the European Disability Forum (expert 7), the card's scope has been expanded to include access to support services – however, only in cases where the person is taking part in a (short-term) EU Mobility Programme such as Erasmus+, not permanently. Thus, 'the red line' regarding access to services is permanence. This has been confirmed by expert 5, who participated in the negotiations within the Council working group on the European Disability Card.

To answer the second question of who supports the introduction of the card, opinions and public statements from various stakeholders, not only interviewed for this thesis, have been analysed¹⁸². Interestingly, those statements available

¹⁸¹ Council of the European Union Doc. No. 6272/24 Analysis of the final compromise text on the Proposal establishing the European Disability Card

¹⁸² The European Commission launched a public consultation from Februar 10th to May 05th, 2023. The outcome answers have been retrieved from: https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/13517-European-disability-card/public-consultation_en

to the public show almost universal support for the card. The EESC even called upon the Commission to choose a legally binding regulatory instrument to ensure that there are no differences in the implementation at the national level. (EESC, 2023, paragraph 1.6)¹⁸³.

Neither does the analysis show significant differences along party lines. For example, the Rapporteur for the Committee of the Regions on the European Disability Rights Agenda¹⁸⁴, the Major of the Italian town Ciampino Daniela Ballico stated that she “*hope[s] that by 2023 the European Disability Card will be fully implemented, which would finally make it easier to provide services and freedom of movement and residence [for disabled people] within the states of the European Union*” (Ballico, 2023)¹⁸⁵. This is remarkable because Ms. Ballico is a Member of the Italian Eurosceptic Lega Party and a Member of the European Conservatives and Reformists Group, which was founded in 2009 to reform the EU based on national sovereignty.

This brings us to the third question: If there is such broad support for the European Disability Card, does it have a harmonizing effect on policies regarding access to assistance services? First and foremost, the card is designed in a way that does not replace but complements national disability cards. Not only does that ensure that the EU disability card will not lead to a disadvantage, but it also opens the way for further extending the card to other areas not yet within the card’s scope. In the discussions leading up to the legislative agreement, the member states have committed themselves to further assess the remaining gaps in the free movement of persons with disabilities, such as the portability of disability-related support when moving to another EU country. For now, member states may voluntarily decide to extend the use of the Card to longer stays.

Finally, what are the Card’s limits, and could its introduction ease permanent residence in the future? As can be expected from any new piece of legislation, and despite its widespread support, the European Disability Card has not been without criticism. The obvious shortcoming is that, although it eases the mutual

¹⁸³ Document number SOC/765-EESC-2023

¹⁸⁴ Official Journal of the European Union, July 27th, 2021. Issue 2021/C 300/06

¹⁸⁵ *Statement* during 144th plenary session of the Committee of the Regions on May 6th, 2021

recognition of disability status, the Card does not resolve the residence trap for a disabled person who cannot participate in the so-called first labour market. According to the European Disability Forum, this point has been made to policymakers; however, various experts (3, 5, 6, 7, and 10) have noted that there has been no realistic debate around this issue.

Additionally, even if the person has a permanent residence permit, there is a significant time gap between leaving the state of origin (and thus the providers of essential services) and having access to support services in the host state. More often than not, disabled people must undergo lengthy 'reassessment' processes, during which they are not entitled to receive any form of support related to disability. One of the key demands by the European Disability Forum has been to include temporary access to disability support and allowances to close this gap (expert 7). At a webinar concerning the EU Disability Card, the representative from the Commission ensured that this demand has been considered in the draft (expert 1). However, despite all efforts by disability lobbyists, this aspect has not been incorporated into the Regulation. The European Disability Forum has therefore announced that it will "*continue its fight for full freedom of movement*" (EDF Website, 2023).

The Interviews conducted for this thesis have also shown contrasting views on the Card's potential impact on disabled people in practice. Some experts, such as MEP Katrin Langensiepen (expert 3), as well as a policy adviser to MEP Gabriele Bischoff (expert 4), were very enthusiastic about this achievement. They pointed out that the card will ensure the mutual recognition of disability status in all services and facilities where nationals can get preferential conditions. This is indeed a clear improvement from the pilot project, which had a restrictive list of services. Further positive aspects include respecting the person's privacy and non-disclosure of the disability type despite the mutual recognition. This could prevent potentially humiliating assessment procedures. This brought the EDF's Vice president Gunta Anca to conclude that "*The European Disability Card is a promise of European citizenship and better freedom of movement for millions of people*" (EDF Vice-President Gunta Anca, 2023).

In contrast, others, such as the interviewed EESC member (expert 6), expressed scepticism regarding the card's real impact. In her view, evidence that the EU Disability Card will be more than a piece of plastic still needs to be provided, especially considering the card's limitations regarding access to services, including personal assistance. This view is shared by some disability lobbyists (experts 9, 10).

Last but not least, it is worth remembering the time frame in which any effect of the EU disability card can be expected. While the Card is without doubt a step in the direction of better including disabled people in European society by means of mutual recognition of the disability status, it will take a long time before the effects become visible. After the adoption of the final text, there will be 30 months to transpose the legislation into national law, plus an additional 12 months to provide the cards eventually. Thus, it will take until 2028 for the EU disability card to be handed out to those eligible. An extension of the EU disability card's scope to areas such as access to personal assistance cannot be expected before the fourth decade of the century.

2.3.4 Potential steps towards the exportability of personal assistance

Nevertheless, many scholars have discussed possible next steps towards the true exportability of SSGI, including personal assistance (e.g. van den Gronden, 2013; Neergaard, 2013). For that sake let us remember the area of tension, which the European Parliament has formulated as early as 2011: *“in the case of SSGI, there are two contrasting factors which have to be reconciled: on the one hand, the principle of subsidiarity, which upholds the national public authorities’ freedom to define, organise and finance SSGI as they see fit, [...], on the other hand, the responsibility incumbent on the Community and the member states for their respective areas of competence under the Treaty.”* (European Parliament, 2011)¹⁸⁶

In this resolution, the European Parliament has delicately identified the core problem: Maintaining the competence to define, organise, and finance SSGI is essentially maintaining the European Social Model. Nevertheless, the member

¹⁸⁶ European Parliament Resolution on the future of social services of general interest, July 5th, 2011

states also committed themselves by signing the EU treaties to enhance the rights of all European citizens, including disabled people.

To overcome this supposed deadlock, Schiek (2020) has explored the EU's competence regime for SSGI. She argues that an EU constitution of social governance should create mixed responsibilities so that the EU, its member states and actors from civil society support each other in creating preconditions for social integration in the EU (Schiek, 2020, p. 73f.) To understand her reasoning, let us recall the two comprising elements of SSGI as defined by the EU Commission:

- statutory and complementary social security systems addressing 'main risks of life';
- essential services supplied directly to the person.

Both elements are in a certain way restrictive. 'Risks of life' are only those that lead to a loss of income for employees, for example, a severe impairment that leads to a disability. The 'services provided to persons' replace services that the family or close relatives otherwise provide. Schiek points out that this mirrors "*a narrow conception of the welfare state in the literal sense, according to which it addresses social risks once they realise, with limited preventive aspirations, let alone aspirations to achieve an inclusive society*" (Schiek, 2020, p. 77).

For disabled people, this narrow definition of SSGI has direct consequences. Member states can exclude SSGI (including personal assistance) from binding EU legislation such as state aid rules or public procurement, because these services are assumed to be a compensation for risks. Following the EU treaties, there are therefore only limited possibilities to legislate SSGI specifically designed for disabled people. The Lisbon treaty grants the EU only an assisting role to "*support and complement the activities of the member states in [...] the integration of persons excluded from the labour market*" (Art. 153 (h) TFEU). As has been pointed out before, there is no distinction made between severely disabled people and other persons who are seen as being 'at risk of life'. Instead, multiple scholars argue that SSGI should serve the higher purpose of including all citizens to fully participate in society, because they play a central role in achieving solidarity and social inclusion in the EU (Ross, 2013, Bauby,

2013; van den Gronden, 2013; Neergaard, 2013; Schiek, 2020). By better regulating SSGI, the EU could enhance the balance between economic freedoms and social rights and thus contribute to strengthening social cohesion.

This brings us to discuss possible options to ensure that disabled people can access assistance services abroad. The analysis of EU legislation has already shown insufficient access to SSGI in cross-border situations and limited expectations for significant change. For that sake, the following thoughts on overcoming this accessibility-trap are neither based on the legislative status quo nor political reality but solely serve as options to be discussed.

Beside this insufficiency, the analysis has shown that the EU's approach towards SSGI is essentially the result of implementing three underlying goals of EU disability policy:

- Fostering coordination between the member states
- Mainstreaming of disability policies
- Organising SSGI on a local level

While stakeholders in the disability field widely support these goals, there are also shortcomings: First, cooperation between national SSGI to enable free movement already exceeds the pure coordination of social security systems through merely individual rights. However, the result is still far from a feasible solution for those needing access to these services. Instead of fostering coordination, *“a further step would consist in creating EU level or transnational (regional) SSGI”* (Schiek, 2020, p. 88).

Secondly, although mainstreaming disability policies is a declared goal in the EU disability rights agenda 2021-2030 and widely supported (e.g. experts 6, 7, 9, and 10), it also aggravates introducing disability-specific legislation. This includes the harmonisation of disability-specific services such as personal assistance. Thus, it may be argued that the logic of mainstreaming has partially resulted in the exclusion of disability specific SSGI from the scope of the EU Disability Card.

Third, the demand for social services to be organized locally derives from the claim to include disabled people in local society. While this is, in theory, a progressive approach, in practice, this mantra translates into an obligation for

disabled people to remain local. When SSGI for disabled people are organised by local actors according to individual needs, it obligates the receivers of these services to use them. This affects this thesis's core: A theoretical (or legal) obligation to receive services at a particular location is a real barrier to free movement. Instead, coordinated governance on multiple levels (horizontally and vertically) is needed in cross-border situations, for which the Open Method of Coordination is one available tool (Kazepov, 2010).

Based on these thoughts, EU rules on SSGI for disabled people appear to be desirable, at least in cross-border situations (van den Gronden, 2013; Bauby, 2013). As Schiek phrased it, "*SSGI [...] are particularly important to further social inclusion and social protection at national levels. However, if the EU is to achieve its new objectives of social justice and social inclusion, it is not sufficient to pursue these objectives at national levels. Welfare regimes based on national closure will lead to two-tier citizenship rights and inhibit free movement of persons throughout the EU.*" (Schiek, 2013, p. 91/92).

Obviously, EU rules need a legal basis. For that sake, classifying SSGI as SGEI (see Figure 25: Definition of Services of General Interest (SGI)) would grant the EU institutions legislative competences to further integrate this field according to the EU treaties (Neergaard, 2013). To ensure accessibility to assistance services for disabled people, the classification of what constitutes an SGEI needs to be taken at the EU level to achieve homogeneity and legal certainty for recipients of SSGI. Furthermore, to regulate access to assistance services for disabled people, the EU needs to dismantle the notion of an 'asymmetrical relationship' between service providers and recipients, but view disabled people as equal to others, while being in an inaccessible environment.

Under these conditions, three practical solutions are to be discussed. They are, however, solely the thoughts from this thesis's author and, to his knowledge, have not (yet) been discussed with policymakers or within the European Disability Forum:

Option	Advantage	Disadvantage
<p>Special residence right</p> <p>The disability status is universally recognized and is accompanied by an automatic right of residence</p>	<p>The principle of equal treatment would ensure equal access to assistance services in the host state</p>	<p>Indirect discrimination against non-disabled, economically inactive people who are not active on the labour market</p>
<p>Reimbursement¹⁸⁷</p> <p>The state of origin must bear costs.</p>	<p>The person has ‘sufficient means’ abroad in the sense of the EU Treaties and therefore is no financial burden to the host state</p>	<p>Costs for assistance services may be higher in the host state than in the country of origin, especially considering income and exchange rates. This may lead to a disproportionate financial burden on the state of origin</p>
<p>European disability fund</p> <p>Creation of a “European disability fund” from which the costs for assistance services in cross-border situations will be borne. This could resemble the Erasmus+ program, which promotes cross-border activities of students and athletes.</p>	<p>Equal access for disabled people to assistance services. Proportionate share of costs for assistance services between the member states.</p>	<p>Dependency on European funding and potentially high administrative burden.</p>

Figure 26: Possible solutions to overcome the accessibility-trap to SSGI

The first of these options seems highly unlikely due to a paradox: On the one side, the European Disability Card facilitates the mutual recognition of the disability status when traveling abroad. A ‘special residence right’ combined with the principle of equal treatment would enable the moving person to reside abroad. On the other hand, however, the national differences remain regarding how disability is assessed. A ‘special residence right’ could therefore lead to a situation in which a foreign person with certain impairments has a disability status that is accepted by the host state, while the disability status of a domestic

¹⁸⁷ This option is equivalent to the rules that apply between the federal states of Germany. The costs for living for economically inactive disabled people are to be reimbursed by the federal state of origin.

person with similar impairments is not recognized. Therefore, the foreign person would have access to disability-related SSGI, while the domestic person would not be granted access to these services. This would most likely lead to intense envy and could not be in the interest of service receivers or EU policymakers.

The second option is to reimburse the costs for SSGI in cross-border situations by the host state's authorities. From the service receivers' perspective, this option is favourable because it enables them to receive personal assistance abroad without having to deal with potentially complicated administrative burdens (expert 7). This model is similar to that in Germany, where a disabled person who receives any form of social benefit moves from one county to another. The service provider invoices the services rendered at the home county's social services department. Thus, this could serve as a model to be scaled up to the EU level. However, the precondition for this option is a certain homogeneity of SSGI in terms of costs and scope of the service. Even within the German counties, there are occasional resentments when a local social service department is obliged to refinance services rendered elsewhere, even though the person might have moved years or even decades earlier. Additionally, it brings along an administrative burden to service providers, who must invoice the service for each county individually according to that department's requirements. On a European scale with different languages (and even font types), this is impossible for service providers to carry out (expert 14).

This brings us to the third option, creating a 'European Disability Fund'. The idea is that this EU fund would cover costs for assistance services in cross-border situations. In its design, it could resemble the Erasmus+ program, which similarly promotes cross-border activities of students and athletes, yet for a permanent residence instead of a limited period. However, such a step would indeed challenge the European Social Model to its core because it would arguably be no less than the creation of the first 'European Social Fund' that is not governed by the member states, but by EU institutions.

Autonomy for disabled and non-disabled people alike is not to be understood as complete independence but as the ability to realize independent choices with support from others when needed. For many disabled people, this support comes in the form of personal assistance services, making access to adequate services when moving abroad a crucial element of the autonomy dimension of being a European citizen.

The analysis of the autonomy dimension has shown how the EU fits assistance services into the legal framework of SSGI and how they relate to other services. It becomes clear that the European Commission does not see assistance services for disabled people on an equal footing with other services. Instead, insufficient access results from the assumption of an 'unequal relationship' between service providers and their receivers. Essentially, this downgrading of service receivers prevents SSGI (including assistance services for disabled people) from further integration.

Nevertheless, the differentiation of specific aspects of accessibility to services has also shown selective progress in EU legislation, particularly the European Accessibility Act (EEA). While the EEA did not address economic and social accessibility, aspects of physical accessibility, communication, and information have been improved. There are signs in the political debate that these aspects may have a spill-over effect on economic and social accessibility, yet this remains speculative.

Regarding the reality of access to personal assistance beyond legislative entitlements, there are substantial differences between the member states regarding the scope and the quality of these services. This is often a significant non-legal barrier for disabled people to move abroad. Many EU member states have such a considerable backlog in organising personal assistance schemes domestically that coordinating these schemes in cross-border situations seems almost pointless.

The introduction of the European disability card has been a key attempt to ease the cross-border mobility of disabled people. Therefore, the legislative process

has been analysed to determine the willingness to sacrifice competences vis-à-vis red lines during the negotiations. While assistance services have not been included in the card's scope despite demands from stakeholders, there is one significant achievement regarding the research question: the universal recognition of disability status within the EU. However, universal recognition is not to be confused with introducing a universal approach to disability.

Finally, potential next steps to overcome the current lack of accessibility for people have been discussed. Under the precondition that SSGI in general and personal assistance in particular are recognized as SGEI by the EU, the most promising option would be the set-up of a 'European Disability Fund' from which these services could be refinanced in cross-border situations.

Research Layout	Part I: Meta- or pre-political factors	Part II: Factors related to institutional or policy design	Part III: Factors related to the implementation of the relevant policy
Research Topic	Representation and political lobby of disabled people in EU policymaking	Subcategories of disability-related policy <ul style="list-style-type: none"> • Self-determination / non-discrimination • Social security / Cash transfer • Autonomy / Personal assistance 	Euregio Meuse-Rhine (DE, NL, BE) as best-case examples for cross-border coordination in economic, cultural, and social matters.
Guiding Question	Is cross-border mobility of disabled people a real problem and have disabled people the means to bring this topic on the political agenda?	Does the subsidiarity principle contradict citizens' rights at the expense of disabled people, and are there attempts to challenge the ESM's status quo?	Does intensified coordination enable disabled people to exercise their rights as European Citizens?
Independent Variable	Representation of disabled people on EU level and their access to EU policymakers	EU policy fields: <ul style="list-style-type: none"> • Anti-discrimination and equal treatment • Coordination of social systems • Accessibility to social services (SSGI) 	Coordination between local actors (public authorities, service providers)
Dependent Variable	Problem-awareness by EU policymakers and disability-related policy agenda	<i>De jure</i> ability of persons with disability to move and reside abroad	<i>De facto</i> ability of persons with disabilities to move abroad
Analytical Tool	Analysis of Disability Lobby and its impact on EU Disability Strategies; Expert interviews with key stakeholders	Analysis of legislative acts and stakeholder's opinions; Expert interviews with EU officials, elected MEPs and EESC members, Council representatives	Quantitative analysis of affected people, qualitative analysis of disability systems within the EMR; Expert interviews with local officials and service providers.
Relevance to Research Question	Is the research topic regarded as relevant? Who is challenging the ESM's status quo regarding disability?	How is the issue of freedom of movement affected by disability-related EU policies, and where is it challenged?	How do European policies affect Active European Citizenship of disabled people in practice?

Figure 27: Part III: Summary Methodological Research Layout

Part III: European disability policies in practice

“The EU is a very nice project. It should grant equal rights, equality for nations and for all citizens, including disabled people. For this, we not only need legal guarantees, but it must also be implemented in practice - and that is the problem.” (MEP Seán Kelly, 2023)¹⁸⁸

3.1 Active European citizenship in the Euroregion Meuse-Rhine

Having analysed the pre-political aims of European disability policies and their implementation in EU law, the thesis's final part concerns the actual impact of these policies in practice. Given the individual components and circumstances of every person wanting to move and reside abroad, this final assessment has natural limitations. Nevertheless, with the topic's increasing significance, the availability of relevant data has improved (e.g., Tøssebro, 2017; Halvorsen et al., 2018).

Among those to measure the actual impact of European Disability policies has been the European Court of Auditors (ECA). In a special report¹⁸⁹ published in June 2023, the auditors assessed the effectiveness of the EU Commission's action regarding supporting disabled people. Essentially, the auditors wanted to determine whether the EU legislation, as laid out in Analysis Part II of this thesis, is based on adequate information. For that reason, they contrasted the criteria for granting disability status in different member states to assess whether these criteria allowed for mutual recognition of the disability status when moving to another member state. Furthermore, the court analysed the available data on disability derived from the different national approaches to

¹⁸⁸ Statement at the plenary session on March 15th, 2023, of the European Parliament on the debate regarding the equal treatment directive of 2008

¹⁸⁹ European Court of Auditors Special report 20/2023

disability. The data has been used by Eurostat and subsequently by the EU Commission.¹⁹⁰

First and foremost, the auditors identified shortcomings in the EU statistics and criticized the coverage, frequency, and depth of detail of the available datasets on disability. According to the Court, “*these differences in data may undermine the mutual recognition of disability status across the EU*” (European Court of Auditors, 2023, p. 4). Since this is a key achievement of the European Disability Rights Agenda and its implementation through the European Disability Card, it is striking that an EU agency is among the first to question the value of this Card simply due to the lack of comparability. Thus, this was a key issue during the interviews with public authorities and stakeholders conducted for the upcoming analysis (experts 11, 12, 13, and 14).

After evaluating the data, the Auditors contrasted the evaluation of the 2010-2020 Disability Strategy to the Design of the 2021-2030 Strategy¹⁹¹. They analysed whether the available EU funding tools effectively matched the needs of disabled persons. Overall, the European Court of Auditors came to the disilluminating conclusion, that despite all political commitment, “*there has been no significant improvement in recent years in key equality indicators across the EU, such as the disability employment gap or risk of poverty*” (European Court of Auditors, 2023, p. 9).

Nevertheless, while the ECA’s assessment across the entire EU may reflect the average development, there could also be challenges in cross-border situations that individual stories have in common, as well as best practices that could be applied in similar situations. For that sake, this thesis’s final chapter builds upon this report with an analysis of one specific European region, namely the Euroregion Meuse-Rhine (EMR). This analysis includes a quantitative assessment of the topic’s dimension within the EMR, followed by a comparison of the various disability systems to identify potential barriers that disabled people may face when moving from one EMR region to another. Furthermore, the analysis includes an assessment of how cooperation channels within the

¹⁹⁰ E.g., Exploring statistics on disability and social participation, February 3rd, 2025. Retrieved from: <https://ec.europa.eu/eurostat/en/web/products-eurostat-news/w/ddn-20250203-1>

¹⁹¹ See Chapter **Fehler! Verweisquelle konnte nicht gefunden werden**. 1.3.3 and 1.3.4

EMR can help those who move abroad overcome these barriers. Eventually, the findings will be discussed with local authorities and practitioners, including a service provider who has experienced the challenges and opportunities in a cross-border situation.

The EMR is located at the border triangle of Germany, the Netherlands, and Belgium. It comprises five regions: The German province of Aachen, the Dutch province of Limburg, and the three Belgian provinces of Limburg, Liège, and East Belgium. Within this region of max. 150 km beeline live around 4 million inhabitants. Interestingly, this area's three major spoken languages are not split along state borders. The Dutch and Belgian provinces that share the same name 'Limburg' also share the same language (Dutch / Flemish), while German is spoken in Aachen and East Belgium. Only Liège is French-speaking.

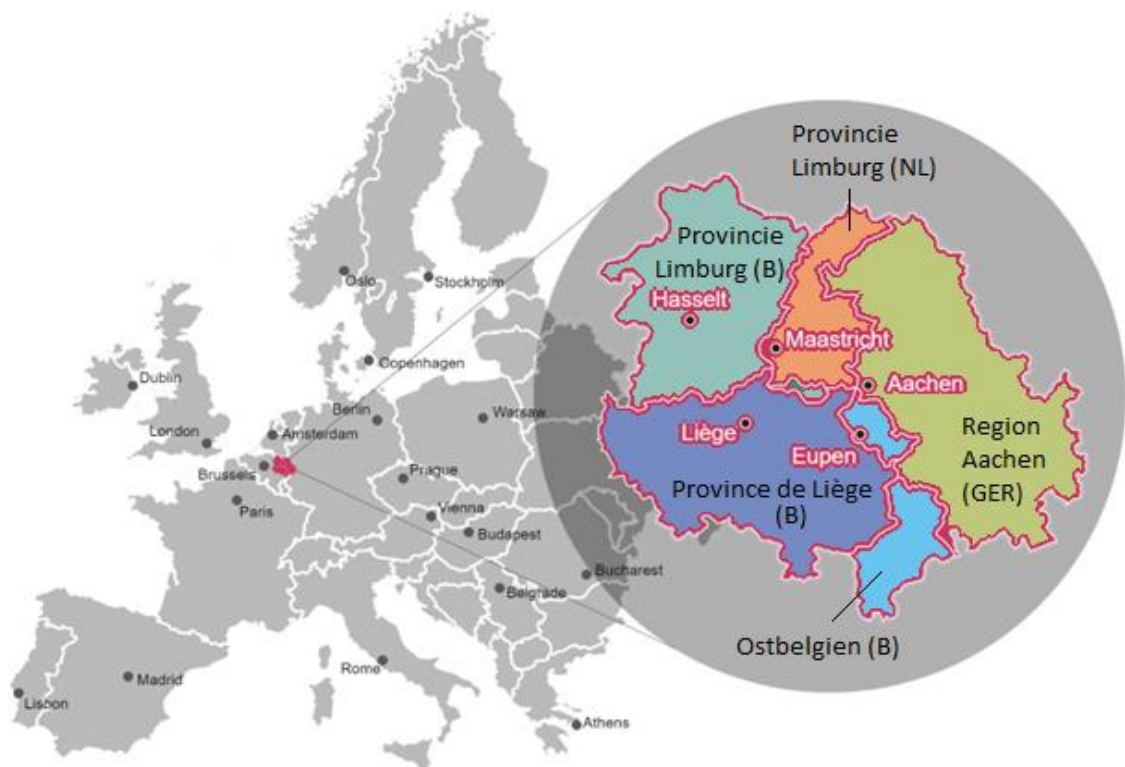


Figure 28: Euregio Meuse-Rhine (EMR)¹⁹²

Since its establishment 1976 as a Euroregion, the EMR's member regions have coordinated their policies on various issues. In 2013, they formulated a strategy to intensify cooperation in cross-border situations (Lenkungsgruppe EMR 2020,

¹⁹² Retrieved from <https://youregion-emr.eu/>

2013, p. 32f.). Two key topics of the so-called 'EMR 2020 Strategy' have been the labour market and education, as well as healthcare, including improving the cooperation between domestic and institutional care services. While disability is not explicitly mentioned in the EMR strategy, disabled people are often disproportionately affected by some of these policy fields. In the region of Aachen alone live around 6.500 people with severe mental disabilities, as well as around 3.800 people with severe psychological disability. More than half of them are of working age.¹⁹³ Suppose they want to participate in the integration process, which the EMR aims to promote. In that case, the question of whether the neighbouring regions recognize their disability status and the entitlements that come with it becomes crucial.

Therefore, the reason for choosing the EMR as an example for assessing cross-border activities of disabled people in practice is threefold: First, although being a small region, it includes three countries and three different languages that do not correspond with the state borders. Thus, due to language barriers within Belgium, there are potentially higher incentives to move abroad than within the home country. Secondly, within the different EMR regions, there are significant differences within the social systems, including all differences in providing social security and disability-related services. Thus, the region offers the opportunity to analyse whether the bi- or even multilateral alignment of different policies across state borders is possible. The third reason is rather practical: Being one of the oldest so-called Euroregions, the EMR has established cooperation processes in many fields, including employment, healthcare, and social security (expert 11, EMR annual audit, 2022). Thus, it is assumed that the experiences hindering the free movement of disabled persons are likely to be likewise applicable in other European regions with less established cooperation channels between public authorities. At the same time, the EMR is the most likely region to learn from regarding best practices.

This chapter's analysis of how disabled people may move or not move within the EMR aims to answer three questions:

¹⁹³ Statistic on severe disabilities in north-rhine Westphalia 2017

- What are the key differences in disability-related policies between the regions that hamper cooperation?
- Is the disadvantage of EMR citizens through the current European Social Model (ESM) of a relevant magnitude?
- What are the experiences of those confronted with the problem in practice?

3.1.1 A comparison of disability- and inclusion policies in the EMR

To answer the first question, the following sections offer a comparative analysis of the disability systems in the four EMR districts regarding the three dimensions of active citizenship: self-determination, autonomy, and security (see chapter 'The Three Levels of Active European Citizenship'). More concretely, the analysis compares the national, regional, and local authorities involved, the approach to disability, access to social assistance services, and the possibilities of receiving cash payments.

Dutch Limburg

Like the European institutions, the Dutch government does not define disability. Instead, the responsible ministry for Health, well-being, and Sports refers to the UN Convention, which recognizes that "*disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others*" (UNCRPD, Preamble 'e'). Strikingly, while the Dutch federal government has signed the UNCRPD, it has not ratified the Optional Protocol of the UNCRPD, which sets up a mechanism for individual complaints.

Instead, it has delegated the responsibility to the Dutch communities through the 'Social Support Act'¹⁹⁴. If a person feels the need for any form of assistance, he/she is to address the local community. Together, the community assesses the aid needs, occasionally supported by the Ministry of Health, Well-being, and Sports.¹⁹⁵ The Dutch EMR province of Limburg consists of 31 such

¹⁹⁴ Wet maatschappelijke ondersteuning (WMO)

¹⁹⁵ Ministerie van Volksgezondheid, Welzijn en Sport (VWS)

communities. Thus, a foreign person who wishes to reside in Limburg has different contact persons, depending on where he/she resides.

The role of the communities, however, is mainly coordinative, while the assessments are conducted elsewhere. The reasoning behind this is that in the Netherlands, disability assessment depends on its purpose. Because of this approach, there are various assessment forms, ranging from an assessment of work-related disability¹⁹⁶, the assessment of long-term or residential care, to an assessment of social support needs. As a result, different authorities are responsible for the respective needs assessment (Smits, 2019, p. 2). For example, a work-related disability is certified by the autonomous administrative authority responsible for executing employees' insurance (UMV)¹⁹⁷. However, an operating foundation called 'Together Unlimited'¹⁹⁸ assesses the need for residential care in the EMR. Furthermore, the disability assessment form also differs among the various Dutch actors. While the UMV's assessment is mainly based on a paper-based 'checklist', other assessments require personal interaction by service providers, medical doctors, or civil servants.

Thus, the Netherlands (including Dutch Limburg) has implemented a strong needs-oriented approach to disability that not only takes the individual circumstance into account, but also the purpose of the assessment itself. Following this approach, the Dutch law does not differentiate between 'groups of impairment'. Therefore, there is no need for a senior citizen to be assigned to the 'care sector', nor for a person with other impairments to be given a 'disability status'. That is a sharp contrast to the other EMR provinces and impedes the recognition of the disability status from the neighbouring provinces in Belgium and Germany.

The decentralized and needs-oriented structuring of assistance implies, at least in theory, a certain degree of self-determination. For example, those who are entitled to receive disability-related institutional care do not necessarily have to reside in such a residential setting. Instead, service receivers may also opt for a direct payment and organize their care in their own home with that payment

¹⁹⁶ Register arbeidshandicapten

¹⁹⁷ Uitvoeringsinstituut Werknemersverzekeringen (UMV)

¹⁹⁸ Stichting Samen Onbeperkt

(Smits, 2020, p. 2). Some service providers offer to let apartments to their clients. However, in reality, this freedom of choice is limited, as the vast majority of eligible people are offered places in care homes without an alternative, and thus without alternative options to choose from. Additionally, some of the biggest providers faced economic difficulties, causing them to reduce their portfolios in deinstitutionalized settings and instead focus on care homes with shared living rooms and shared care workers.¹⁹⁹ Within the EMR, this can be well observed. Maastricht's former public 'Service point for disabled people'²⁰⁰ has been closed. Instead, the website now refers directly to the leading service provider.

The Dutch national expert on disability advising the European Commission, Smits, points out that to overcome this trend, the Dutch government would need to reallocate financial means to deinstitutionalized settings. However, he concludes that *"in general, [in the Netherlands] there is no awareness among policymakers, care providers and DPO's about the imperative of article 19 UNCRPD; the right to live independently and the need to transition from institutional care to community-based support"* (Smits, 2019, p. 16).

Another difficulty deriving from the decentralized approach concerns the quality of social services such as integration assistance. Despite the shared responsibility of several authorities, there are no defined standards on the federal level in the Netherlands. (Smits, 2019). Instead, the municipalities and other stakeholders, such as the national public authority for unemployment and disability reintegration services (UWV), are free to decide on the level of provision and the quality of services they provide. The only requirement is an annual client satisfaction review, consisting of a short set of questions and a rating system. The operating service provider must prove the use of adequate quality management tools, but is not bound to specific quality criteria. However, when the operating association controls the system that is supposed to ensure the service quality, it cannot be objective. Thus, even when they have access to disability-related services, foreigners residing in Dutch Limburg have no guarantee that these services adequately match their needs.

¹⁹⁹ These providers are named Reigersdaal and Arduin

²⁰⁰ Service punt gehandicaptten

Overall, “[Dutch] quality assurance systems are process-oriented, not outcome-oriented” (Smits, 2024 p. 17). In consequence, however, the situation in which social service receivers are put does not comply with the principles of Art 19 UNCRPD. Therefore, it is unsurprising that the Netherlands is one of the few remaining EU countries that have ratified the aforementioned Optional Protocol of the UNCRPD. In fact, in an answer to the UN, the Dutch government explicitly refers to concerns regarding the financial and legal implications of establishing such a mechanism in the Netherlands, clearly stating that “*the [Dutch] government has no intention of ratifying it*” (Dutch government, 2024)²⁰¹.

Germany / Province Aachen

Unlike the Netherlands, Germany has signed the UNCRPD and the Optional Protocol, enabling individual complaints in non-compliance with the Convention Standards. For that sake, Germany implemented the UNCRPD between 2017 and 2023 through the federal participation law (BTHG).²⁰² To understand the reasoning behind the BTHG, one needs to recognize that German social law is divided into 12 sections, the social security codes (SGB) on a federal level²⁰³. Each section deals with different aspects of social security, ranging from rehabilitation and medical aid to income support and housing. A key aspect of the BTHG has been to remove disability-related integration support from the section of social aid (SGB XII) and instead assign it to the section concerning rehabilitation (SGB IX). This demonstrates a new approach towards disability. Rather than ‘caring’ for disabled people, the intention is to integrate them into society (Deutscher Verein für öffentliche und private Fürsorge e.V., n.d.).

Furthermore, this legislation set up a new legal basis for the integration of disabled people in society and, therefore, is a major step in German disability policy. The national experts who advise the EU Commission concluded that through the BTHG, “*the equal, full and effective participation of disabled people in political, social, economic and cultural life, with an independent and self-determined lifestyle was strengthened*” (Hirschberg; Welti, 2024, p. 7). The new

²⁰¹ United Nations Committee of the Rights of Persons with Disabilities, 31st session from August 12th to September 6th, 2024.

²⁰² Bundesteilhabegesetz

²⁰³ Sozialgesetzbücher (SGB)

approach indeed shows a significant change in German disability policy, because it builds the basis to reform the German assistance system from a supply-oriented system to a demand-oriented social market (Rosken, 2020). This should, in theory, foster the ability to choose from different service providers and enhance the quality of social services through competition.

A second important aspect of the BTHG is the redefinition of disability as *“physical, mental, intellectual or sensory impairments, which in interaction with attitudinal and environmental barriers, can very likely prevent [the person] from participating in society on an equal basis for more than six months. An impairment (...) exists if the state of body and health deviates from the state typical for age.”*²⁰⁴ This definition is in alignment with the WHO's ICF approach to disability.

However, having outlined the theory of German disability law, the practice is rather complex. First, while the general definition of disability has been agreed upon on the federal level, the application is subject to German state law. In 2017, North Rhine-Westphalia, which includes the EMR province of Aachen, developed a tool to determine the individual needs of a disabled person.²⁰⁵ Therefore, this tool is used to define a person's disability as well as their entitlements to social services. A foreign person could apply for disability-related services according to SGB IX, but needs to undergo the regional disability assessment (Rosken, 2020).

Moving to the German EMR province became even more complicated through the BTHG, because a disabled person now needs to apply at various contact points, depending on his/her needs. For example, assessing the disability status and certain integrational services is the city of Aachen's responsibility. Other disability-related services, such as housing or admission to an institutional setting, are organized by the state agency Landschaftsverband Rheinland (LVR). This agency is also responsible for the social security issues of disabled persons. However, a different administrative city department in Aachen grants certain social aid, such as assistance with living expenses.

²⁰⁴ Sozialgesetzbuch (SGB) IX Rehabilitation und Teilhabe von Menschen mit Behinderungen, § 2 (1)

²⁰⁵ BEI_NRW - Bedarfe ermitteln, Teilhabe gestalten

Furthermore, if the person also needs physical care services, he/she needs to apply for a 'care degree' (Pflegegrad) at a care insurance company. This requires another assessment of the person's care needs. If the care degree is granted, the person can decide between a personal budget to compensate for the care work of family members, or he/she can purchase care services from a care company. Navigating through this bureaucracy is often challenging for disabled Germans or their legal guardians, let alone for foreigners who wish to reside in Germany. National experts from Germany, who advise the EU Commission, have suggested increasing transparency by better involving those affected in the process while simultaneously harmonizing the various, rather complex systems (Schröttle et al., 2019).

Belgium

As previously described in Germany, competencies in disability-related policy fields are also distributed between different levels in Belgium. Thus, a foreign disabled person wanting to reside in Belgium needs to address a variety of authorities depending on the respective issue (Leyseele, 2020; Huys, 2024).

Two actors are involved at a federal level: the Federal Public Service for Social Security (FPS) and the National Institute for Health and Disability Insurance (NIHDI). Most notably, the Belgian Federal Public Service for Social Security conducts the general recognition of disability by assessing body functions. This takes place via a paper-based questionnaire that needs to be filled in and reviewed by a medical doctor²⁰⁶.

The general disability assessment in Belgium considers six criteria of self-management: mobility, diet, self-care, household, interpretation of danger, and social interactions. Each of these criteria is ranked on a scale from 0 to 3 to determine a 'disability score'. Eventually, the doctor makes the final decision about the degree of disability.

Unlike the German and Dutch definitions, not only does this represent a purely medical understanding of disability, but the approach also has a direct financial effect: The scope of disability-related social security benefits is directly linked to

²⁰⁶ The questionnaire can be retrieved from: <https://handicap.belgium.be/fr/reconnaissance-de-votre-handicap>

the individual disability score. The higher the score, the higher the financial scope of disability-related benefits. This also applies to disabled people from the Dutch or German EMR regions who wish to reside in Belgium. To be eligible for disability-related benefits, they must first see a Belgian doctor and apply for benefits at the NIHDI. According to several experts, this process may often take several months (experts 11, 12, and 13). Furthermore, this problem is likely to remain even after the European Disability Card is implemented, because the sole recognition of the disability status does not include the transmission into the Belgian score system.

After the FPS recognized the disability status, the second federal authority involved is the State Institute for Health and Disability Insurance (NIHDI). This institution is responsible for administering Belgium's national schemes for health insurance and disability benefits. Having this mandate, it defines the conditions required to receive certain disability-related benefits, for example, concerning the inability to work and thus, the need to receive wage compensation payments. Part of this task includes combating 'disability fraud', meaning the illegal receipt of disability-related financial aid while also receiving wages.

Non-financial competencies, most notably the person's actual needs assessment, are passed on to the regional level. Each region (Flanders, Wallonia, Brussels, and the German-speaking community) has a different authority and, with that, different rules (Huys, 2024).

Living with Disability in the EU:

Level	Administrative area	Authority	Disability-related competence
Federal responsibility	Federal public service for Social Security (FPS)	General Directorate for Persons with Disabilities	General recognition of disability according to medical assessment Income replacement aid for disabled people (BEE-EB), VAT exemption, tax relief Certificates i.e. for Parking; National Discount Card, public transport, social tariffs for phone, gas, or electricity
	State Institute for Health and Disability Insurance (NIHDI)	Disability insurance	Health and care, rehabilitation and retraining services, Mobility aid
Regional responsibility	Regional Ministries	i.e. Vlaams ministerie voor Onderwijs, Justicie en Werk, Gouvernement de la Fédération Wallonie-Bruxelles	Employment, integration into the workforce, Special education and integrated education
	Regional contact points	Vlaamse Agentschap voor Personen met een Handicap (VAPH) Agence Wallonne pour l'Intégration des Personnes Handicapées (AWIPH) Service bruxellois Personne Handicapée Autonomie Recherchée (PHARE) Dienststelle für selbstbestimmtes Leben der Deutschsprachigen Gemeinschaft	Needs assessment, admission to facilities, personal budget, aids, adjustments of living spaces
Local responsibility	Provincial governments	Ville de Liège, stad Hasselt (Limburg), Stadt Eupen	Developing social infrastructure, accessibility of public places, supervision of service providers, EU cross-border projects such as Interreg

Figure 29: Distribution of disability-related competencies in Belgium

Belgian Limburg

The East-Belgian province of Limburg, which belongs to the EMR, is part of the Belgian region of Flanders. Therefore, the Flemish Agency for People with a Disability (Vlaamse Agentschap voor Personen met een Handicap VAPH) is responsible for assessing and deciding on a person's support needs.

Recognizing the social context of an individual impairment, the agency explicitly refers to the ICF when defining disability as *“any long-term and severe participation problem of a person due to the interplay between functional disorders of a mental, psychological, physical or sensory nature, limitations in the performance of activities and personal and external factors”* (VAPH, 2024)²⁰⁷. Thus, despite making use of the federal disability assessment, *“the VAPH uses its own definition of disability”* (De Bruycker, 2020, p. 6).

In practice, instead of only relying on the assessment of a single physician, the needs assessment is conducted by a multidisciplinary team. The basis for determining the scope of the support is an assessment tool called ‘care value’²⁰⁸. Thus, unlike the purely medical approach and the examination by a physician on the Belgian federal level, on the regional level in Flanders, the needs assessment is not only conducted by a different agency but also based on a different understanding of disability.

While the discrepancy between recognizing disability and assessing the person’s needs may already cause problems, the bureaucratic obstacles for non-Flemish persons who wish to reside in Limburg do not end here. After the needs assessment by the VAPH, determining the actual entitlements is subject to a third agency called ‘child and family’ (kind en gezin). This agency operates 57 service points in Flanders, eight of which are located in different municipalities in the province of Limburg. This local allocation enables the agency to recognize the social context of each person individually. Thus, these local offices must be consulted when moving to Limburg and needing disability-related assistance.

²⁰⁷ <https://www.vaph.be/voorwaarden/handicap>

²⁰⁸ Flemish: “zorgwaarte”

Eventually, these entitlements are translated into a personal budget, with which the person is free to 'purchase' services. Therefore, service receivers retain a certain degree of freedom to choose from multiple service providers (Leyseele, 2020). While this approach shows similarities to the German system of providing disability-related services, it represents a significant barrier to citizens of other EMR regions who are not granted a personal budget and therefore, cannot buy assistance or care services in Belgian Limburg.

Province Liège

Responsible for the recognition of a disability for people from the province of Liège is the Belgian federal Directorate General for Disabled People (Direction Générale Personnes handicapées). As previously explained, this authority lays down a clear procedure for gaining disability status, including the forms that the person's physician must fill out. From these files, the authority derives a 'disability degree' that allows the person to apply for the necessary assistance. On a federal level in Belgium, this model follows a clear medical perspective on disability.

In the region of Wallonia, to which the province of Liège belongs, the procedure to match the person's needs with the provision of adequate services and/or devices lies in the responsibility of the so-called 'Agency for Quality of Living' (L'Agence pour une Vie de Qualité, AViQ). This agency has been renamed from its previous name, 'Walloon Agency for the Integration of disabled people' (Agence wallonne pour l'intégration des personnes handicapées, AWIP), to demonstrate a change in the way of thinking towards disability. Instead of integrating disabled people into existing societal structures, the aim is to change existing structures to avoid disability of impaired persons whenever possible. Thus, like the Belgian region of Flanders, there is a discrepancy between the federal and the regional level regarding the approach towards disability.

While the AViQ does not have the power to grant disability status, the agency coordinates different disability policies, manages the available capacities in Wallonia, authorizes assistance services to disabled people, and supports their families. For that purpose, the agency operates seven local offices. One of

these offices, which serves as the first contact point for disabled people, is in Liège.

However, the AViQ sets clear criteria that applicants must fulfil to receive benefits from AViQ:

- An alteration of his/her mental, sensory, or physical faculties. A medical certificate accompanying the disability status is needed.
- Significant limitations in his/her capacity for social and professional integration
- The person must be younger than 65 when applying for assistance. If the person is older than 65, he/she might be eligible for care services for the elderly but not for integration services for disabled people. While this is unique to Belgium, it corresponds with German legislation.
- The primary residency must be within Wallonia
- The person “*must be of Belgian nationality, be assimilated to a person of Belgian nationality or reside for 5 years without interruption in Belgium*”;(AViQ, 2024)²⁰⁹

The last criterion is a massive barrier to freedom of movement for disabled EU citizens who wish to move to the Walloon region. While “*assimilated to a person of Belgian nationality*” is not defined, it certainly is not equal to EU citizenship. Therefore, within the EMR, the Walloon province of Liège shows the most obvious exclusion of foreigners.

German-speaking community East-Belgium

The Belgian German-speaking community is the smallest within the EMR. With only around 80.000 inhabitants in the entire province, the rural area is home to less than 1 % of the entire Belgian population. Because of this, the community enjoys a special status in many policy fields in Belgium, including social policy.

Concerning assistance services for disabled people, the whole responsibility lies within a single authority, the so-called Agency for Independent Living (Dienststelle für selbstbestimmtes Leben). Because of its small size, the province follows a very informal way of integrating disabled people. Instead of a

²⁰⁹ The requirement can be found at :<https://www.aviq.be/fr/faire-reconnaitre-mon-handicap>

defined assessment procedure, the Agency for Independent Living assesses the individual situation and explores the best possibilities to integrate the person into society. When in doubt, individual agreements are made with the province's social minister, who supervises the agency.

Similar to the approach in Dutch Limburg, disabled people have the first contact points as other people in need of assistance, such as elderly people who need care, homeless people, or other vulnerable groups. For that sake, the definition of disability becomes almost irrelevant.

However, the authority reported that due to the province's limited size, the community has limited options for providing services to disabled people (expert 12). While there are two stationary facilities in St. Vieth and Eupen, not all needs can be matched within the province²¹⁰. There are, for instance, no facilities for severely disabled people who also need intensive care, nor for people with psychological impairments who show challenging behaviour. Thus, not only is there no true freedom of choice, but some German-speaking Belgians live in facilities in Flanders or Wallonia, even though they do not speak the language and have trouble communicating with staff members. This is not only problematic for therapeutic or instructional reasons, but for those disabled people who do not speak several languages, inclusion into society becomes almost impossible.

For that reason, the incentive for disabled people to move across the border to a facility in Germany becomes less a question of equal treatment to non-disabled persons, but the necessity to receive adequate support to live a life worthy of a human being.

²¹⁰ A list of all facilities in East Belgium can be retrieved from:
<https://archiv.dpb.be/Angebote/EinrichtungenundDienste.php>

EMR province	Dutch Limburg	Flemish Limburg	Province of Liège	German-speaking community East-Belgium	Region of Aachen
Responsible authorities	National, regional and local, i.a. UWV, register arbeidshandicaptten, stichting samen onbeperkt Maastricht	FPS, NIHDI, Vlaamse Agentschap voor Personen met een Handicap (VAPH), kind en gezin	FPS, NIHDI, L'Agence pour une Vie de Qualité (AViQ)	FPS, NIHDI, Dienststelle für selbstbestimmtes Leben	Landschaftsverband Rheinland (LVR), city of Aachen, care insurance
Approach / Assessment of Disability	A variety of different disability assessments, depending on context. Strong social/contextual approach	mainly medical perspective, yet recognizing the social context for assessing the individual needs	Medical perspective with a clear scheme to be filled out by a physician.	Solely medical perspective with a clear scheme to be filled out by a physician.	Mainly medical perspective, yet recognizing the social context for assessing the individual needs
Self-determination/ freedom of choice	In theory, freedom of choice, in practice, allocation to providers due to a lack of offers	Freedom to choose from different forms of assistance and service providers	No real freedom of choice, AViQ decides on the scope of assistance	No freedom of choice due to a lack of offers within the province	Freedom to choose from different forms of assistance and service providers
Autonomy / Access to personal assistance	Municipalities decide on access and quality of personal assistance, No real control of quality	Personal assistance services can be purchased with a personal budget, coordinated locally by 'kind en gezin',	AViQ will grant all assistance based on defined criteria and additional requirements related to age, residence, and nationality.	Strong focus on personal assistance in own living space, as residential capacities are limited to two institutions	Needs assessment through a defined tool, through LVR, evaluating the need for personal assistance
Social Security/ Personal budget	Depending on the context, disabled people may opt for cash payment instead of services.	Personal budget for all services, including housing, assistance, and care	No personal budget, direct compensation of costs by the AViQ	No personal budget, individual agreement with the province's minister for social affairs	Personal budget for services, social aid, and personal budget for care services may be chosen

Figure 30: Comparison of disability systems between the EMR provinces

3.1.2 Why individual arrangements are insufficient

Having identified the differences between the regions' disability systems within the EMR, the following analysis approaches the magnitude of these differences. When designing this thesis, a frequent remark has been that only a few disabled people could be hindered from moving abroad, let alone in a comparably small region such as the EMR. On the one hand, discrimination is not measured by the number of people affected, but whether a group is systematically disadvantaged. Thus, the quantification of the problem is irrelevant for designing appropriate countermeasures. On the other hand, it is worth addressing the question of 'who cares?' to grasp the political significance and thus, the likelihood for any countermeasures to be successful.

However, quantifying the problem is challenging for numerous reasons, including the aforementioned inconsistency in defining disability between the EMR regions (Tøssebro, 2017). Equally challenging is finding reliable data, especially considering that this thesis focuses not on an issue that repeatedly occurs but on the very absence of that occurrence. In other words, there is no polling among disabled people who would have wanted to move abroad but could not because of a disability.

Thus, the following analysis will follow a dual approach to find another solution for quantifying the issue: First, it will compare the share of disabled foreigners living in an EMR region to that of non-disabled foreigners. This analysis is complemented by a distinction of various impairments that cause disability and are likely to result in a dependency on social aid and/or social assistance services. Second, the number of social service recipients is complemented by analysing the recipients of (social) integration services. This includes services to temporarily and permanently impaired persons. Like the first approach, evaluating the reception of integration services by nationalities indicates whether EU foreigners might have limited access to these services when they need them.

The data being used is drawn from the German federal statistics for severely disabled people²¹¹. The nationwide dataset has been evaluated with regard to the four German districts that belong to the EMR.

The evaluation shows that out of the 1.27 million inhabitants that live in the German EMR districts, more than 135.000 have a recognized severe disability. This corresponds to a share of approximately 10.6% and thus (unsurprisingly) to the general share within the EU. It can be assumed that, despite different definitions of disability, the proportion is similar in Belgian and Dutch EMR regions. Accordingly, around 400.000 people in the EMR have a severe disability.²¹²

However, is their cross-border mobility truly hindered? The statistical data has been filtered in a second step according to citizenship to answer this question. It is striking that 94% have German citizenship, while only 2% of the severely disabled come from another EU country. In comparison, the proportion of all EU foreigners (disabled and non-disabled) living in Germany is at 6%, about three times higher. Thus, the data shows a significantly lower percentage of disabled EU citizens living abroad, even though the EMR is a border region.

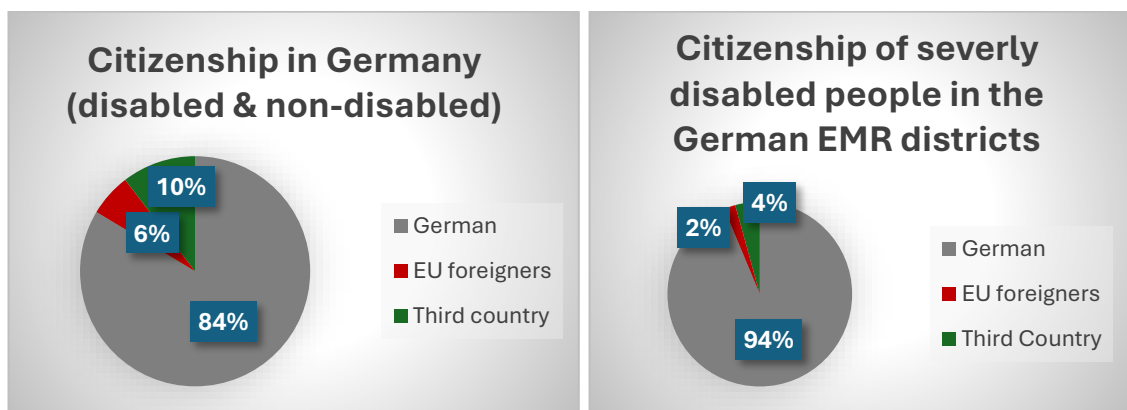


Figure 31: Share of citizenship of severely disabled persons in the EMR (2023)

However, these numbers need to be regarded with some caution. One consideration when interpreting these numbers is that people might as well be born and raised in Germany but have a foreign citizenship due to their

²¹¹ Survey documents H 106 for the statistics of severely disabled people from the reporting years 2020-2022. Special evaluation on request from July 15th, 2024.

²¹² Author's projection based on statistics for severely disabled people in the German EMR districts

(potentially non-disabled) parents. However, excluding this factor would decrease the share of EU foreigners to an even lower share than 2 %. Secondly, the number of 135.000 people includes all severely disabled people, making no distinction of the specific impairment that is causing their disability, nor of the severity level. Thus, those whose disability results from a purely physical impairment, such as the loss of limbs, are equally regarded as those who have a congenital, intellectual impairment, even though their chances on the labour market are significantly different.

Considering the research question of whether the citizens' right of moving and residing abroad challenges the European social model, the available data for the German EMR districts has been assessed regarding some specific groups that face great stigmatization while at the same time being greatly dependent on assistance services and social aid: Severely disabled people with diagnosed disorders of mental development (e.g. learning disorder), mentally ill people with severe psychological impairments such as neuroses, personality or behavioural disorders, and those diagnosed with blindness or severe visual impairment.

Severely impaired citizens in the German EMR districts (2023)	Total	German	Other EU nationals	Third country
Severe disability (total)	135.210	126.715	2.755	5.740
Disorders of mental development (e.g. learning / mental disorder)	4.645	4.280	95	270
Psychological impairments (e.g. neuroses, personality / behavioural disorders)	6.805	6.225	145	435
Blindness or severe visual impairment	2.015	1.850	35	130
Congenital impairment	3.965	3.685	70	210

Figure 32: Citizenship and diagnosed impairment in the German EMR districts (2023)²¹³

²¹³ Source: Survey documents H 106, special evaluation on request

The evaluation shows that these groups account for a total of 13.465 people within the four German EMR districts, or approximately 42.000 people within the entire EMR. Strikingly, the share of EU foreigners in this group is equal to that of all severely disabled people in the EMR, around 2 %, with no statistically significant connection between the type of impairment and citizenship.

While analysing the first data set has illustrated the issue's scope, the second part focuses on its depth. For that sake, the previous analysis is complemented by how the individual's need for support relates to the ability to move within the EMR by assessing their access to social services. For that sake, an additional data set²¹⁴ has been commissioned, focusing on those receiving assistance services. However, due to the way the data was collected, there is no difference in whether those receiving assistance have a certified disability or not.

Service recipients in the German EMR districts (2022)	total	German	Other EU nationals	Third country
Recipients of integration assistance services (total)	15 760	14 780	260	720
Simultaneous receipt of social aid ²¹⁵	220	215	0	5
Services for social participation ²¹⁶	9 255	8 755	150	350

Figure 33: Citizenship of assistance service recipients in the German EMR districts (2022)²¹⁷

According to these numbers, 15.760 people received so-called integration assistance services. More than half of these services aimed to enable the recipients' social participation, while other services included reintegration into

²¹⁴ State Office for Information and Technology North-Rhine Westphalia based on the federal bureau for Statistics. Survey documents EG 11A for the statistics on recipients of integration assistance to SGB IX (from the reporting year 2020). Special evaluation on request from July 31st, 2024.

²¹⁵ According to German Social Code XII

²¹⁶ According to § 113 German Social Code IX

²¹⁷ Source: State Office for Information and Technology North-Rhine Westphalia on basis of federal bureau for statistics. Survey documents EG 11A for the statistics on recipients of integration assistance to SGB IX (from reporting year 2020). Special evaluation on request from July 31st, 2024.

the workforce. Assuming that the share is similar in the Belgian and Dutch EMR regions, the number of integration assistance services within the EMR adds up to roughly 50.000 recipients, of which approximately 30.000 people receive services for social participation. The share of EU foreigners receiving assistance services living in the German EMR districts has been even below the share of severely disabled EU citizens of 2 %.

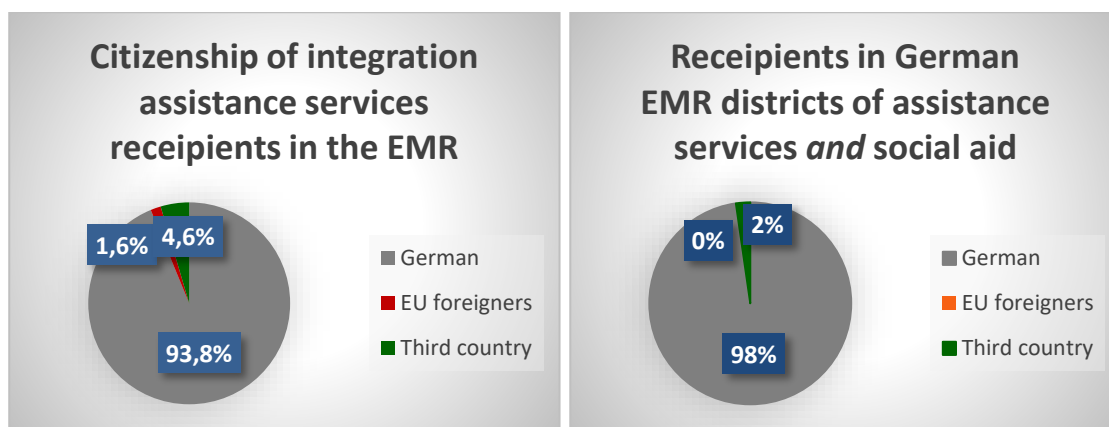


Figure 34: Share of citizenship of integration assistance recipients in the EMR (2022)

How do these numbers contribute to answering the research question of whether disabled people's right to free movement may be a driving force to reform the European Social Model from a charity-based understanding towards a rights-based approach? Several conclusions can be drawn from this data: First, even though the EMR is a border region with established cross-border cooperation in various fields, severe disability remains a harmful factor regarding cross-border mobility. However, severe disability is not an absolute exclusion criterion per se, since the number of EU foreigners is not zero. In other words, disabled people are moving and residing abroad despite their disadvantageous situations, building a push factor to reform the insufficient coordination between national social systems. In this context, the available data from the German EMR districts shows no significant difference between different types of impairment that cause their disability regarding their citizenship abroad. Nor does it appear to make a significant difference whether the impairment is congenital or acquired.

Regarding access to social assistance services, the fact that 260 non-German EU citizens received social services for integration assistance shows that

neither disability nor nationality are *per se* criteria to be excluded from the social system. However, when combining the receipt of assistance services with the simultaneous reception of social aid (for example, to cover living expenses in cases of incapacity to work), the number of EU foreigners living abroad in the German EMR districts hits zero. This illustrates that statistical elevations confirm the theoretical research problem. It also shows that the problem is only absolute in selected areas that potentially include direct cost coverage by the host state in the form of monetary payments. Covering all other costs associated with integrating disabled EU foreigners seems to be neither a judicial nor a political problem, but rather an administrative barrier.

The Euregio Meuse-Rhine (EMR) includes five provinces at the border triangle of Belgium, Germany, and the Netherlands. Established in 1976, it is one of the oldest institutions for cross-border cooperation in the EU of this kind. It therefore serves as a best-case example to answer two central questions regarding the research topic: Are there key differences in disability-related policies that may hamper coordination? And if that is the case, can the resulting disadvantages be solved in individual agreements, or are they of a politically relevant magnitude of a bigger problem?

First, the analysis of the disability policies within the five EMR provinces has shown significant differences. These differences result from different understandings of disability (medical vs. social model, see chapter 1.1). Strikingly, this heterogeneity can be observed horizontally between the three EMR states, as well as between different hierarchical levels within the states. Within Belgium, there are significant differences between the regional disability systems.

Thus, the first question is answered with a strong affirmation. Even within the EMR, a comparably small region, there are multiple barriers to coordinating disability policies. They include the absence of a common approach to disability, legal uncertainty for disabled people when moving abroad, and, in the case of Wallonia, even a direct exclusion of non-Belgian citizens from any disability-related benefit or service. All in all, these barriers potentially deprive disabled

EMR citizens of their rights as European citizens to move and reside abroad on an equal basis to others.

The analysis regarding the second question regarding this issue's magnitude comprises a detailed evaluation of the statistics on severely disabled people in the German EMR province, supplemented by an evaluation of statistics regarding access to integration services. The data shows that the aforementioned barriers affect around 400.000 severely disabled people in the EMR, especially around 30.000 people who receive assistance services for social participation.

Of course, only a small percentage of this group attempts to move and reside abroad. Still, the share of EU foreigners from other EU countries is significantly lower among severely disabled people (2%) compared to the general share of EU foreigners living in Germany (6 %). This indicates that the above-mentioned barriers are measurable and have a scale that cannot be solved solely through case-by-case agreements without a reliable legal basis.

3.2 Experiences with cross-border mobility by regional authorities

Having assessed the different approaches to disability of the five EMR provinces, the resulting differences in disability policy, and the scope of how many EMR citizens face disability-related barriers when moving abroad, this chapter assesses the experiences of 'frontline workers'. There are three guiding questions that this chapter aims to answer: First, how do the experts on the ground experience the coordination between the national social policy systems? In that respect, do EU policies have a noticeable effect, or do (subjective) impressions and felt experiences match with the ECA's estimation that there has been "*no significant improvement in recent years*" (European Court of Auditors, 2023, p. 9)?

Secondly, is the local authorities' general attitude towards the cross-border mobility of disabled persons somewhat supportive or rather disruptive? If they are supportive, how can cooperations such as the EMR offset these barriers?

Finally, the experts interviewed for this chapter (experts 11, 12, 13, and 14), particularly the public servants, were asked whether they experienced a significant change regarding their willingness to find solutions outside legal frameworks or established cooperation mechanisms.

To answer these questions, the local authorities responsible for the implementation of disability policies²¹⁸, as well as the EMR regional office, have been contacted. Some have replied that they had no knowledge of disabled persons in cross-border situations or did not reply at all²¹⁹. On the contrary, others expressed a high interest in talking about the issue due to its significance for their work. The different feedback already contributes to answering the second question: It appears that the necessity to deal with the cross-border mobility of disabled people is experienced unequally. For that sake, the experiences are based in particular on the EMR's head office in Eupen, the coordination centre for disabled people of the city of Aachen²²⁰, and the Agency for Independent Living of the German-speaking Community of Belgium²²¹.

3.2.1 How the EMR supports its citizens in cross-border situations

One stakeholder who demonstrated a high interest in the issue was the central team of the EMR's regional office (expert 11). The team consists of five permanent members from each of the EMR provinces. A counselling centre, the so-called border information point²²², supports them. Established in 2012, these contact points are independent bodies that support and advise citizens on various cross-border topics, including the coordination between different social security systems. According to the EMR representative from the city of Aachen (expert 11), these border information points assisted in approximately 12.000 individual cases in 2023, indicating the general demand for information and support for cross-border mobility. Initially, the project was financed through the EU program 'Interreg'; however, due to its success, it is now permanently

²¹⁸ see Section 3.1.1, Figure 28

²¹⁹ The Dutch stichting samen onbeperkt Maastricht, the Flemish agency 'kin en gezin' in Hasselt, and the Walloon L'Agence pour une Vie de Qualité (AViQ) in Liège showed little interest in the topic.

²²⁰ ‚Leitstelle „Menschen mit Behinderung“ der Stadt Aachen

²²¹ Dienststelle für Selbstbestimmtes Leben (DSL) der Deutschsprachigen Gemeinschaft in Ostbelgien

²²² Grenzfopunkte

financed by the German state of North Rhine-Westphalia and the Dutch Ministry of Economic Affairs. Having this mandate, *“the EMR sees itself as an intermediary between politics, including EU policies, and practical implementation”* (expert 11).

This intermediation takes place in several directions: ‘Top-down’ in the sense of assisting with the implementation of EU policies within the EMR, as well as ‘bottom-up’ in bringing issues and challenges to the attention of policymakers on all levels. For that reason, the representatives of the EMR are frequent guests in Brussels for attending expert conferences to share practical experiences. This is of high value to the EU officials in drafting EU legislation, because *“sometimes [the EMR’s] consultants deal with cases where there is no legal answer. In this case, the EMR is a welcomed guest at the EU Commission in order to pass on these cases and the consequences directly without a procedural filter”* (expert 11). In the past, some of these cases also concerned the situation of disabled people in cross-border situations.

In drafting EU legislation, the EU Commission has occasionally proactively addressed the EMR to share its experience on a specific issue. At the same time, the EMR also has close contact with its clients and local actors, such as social services providers. For instance, as part of the project ‘EUprevent’, the EMR has been in close contact with the local ‘Caritas foundation Euskirchen’ (EMR annual audit, 2022). This ecclesiastical non-profit company assists people with addictive disorders.

The vertical cooperation on the one hand, the EMR also maintains horizontal networks to other border regions, for instance, the counselling centers ‘InfoBest’ at the French-German border in Alsace-Lorraine²²³ and ‘Grenznet’ for the Danish border region Sønderjylland and the German region Schleswig²²⁴. The border regions regularly exchange their experiences on various issues, including coordinating social security benefits. The key question guiding these meetings is whether a certain problem is caused by local circumstances or is equally applicable to other border regions (expert 11). If this is the case, the

²²³ See <https://www.infobest.eu>

²²⁴ See <https://www.region.de>

issue becomes relevant at the EU level and cannot be solved solely by individual arrangements.

When asked about the practice of finding solutions to cross-border problems in cooperation with local authorities, the EMR representatives reported general willingness by the civil servants. According to their experience, "*there are basically no reservations about EU laws and coordination on social issues. This is more of a matter of course. However, there are different opinions and interpretations on various detailed issues*" (expert 11). In some cases, the issue has been brought before the European Court of Justice for clarification.

However, the EMR representatives also try to find solutions when there is no explicit legal basis. This can either result in individual agreements or, if it has EU-wide relevance, the issue may be forwarded to the EU Commission.

A best-case example of such a scenario is the children's hospital in Maastricht, which has been closed due to a significant decline in the number of illnesses. On the one hand, it shows the positive development of fewer children needing medical help. On the other hand, the remaining Dutch patients had to travel a long distance (approximately 140 km) to the closest children's hospital in Nijmegen. Due to the EMR's cooperation, practical arrangements have been made with the EMR-cities Aachen and Hasselt to avoid this burden for the families.

Regarding cross-border situations of disabled people, the EMR referents, as well as the border information points, experience frequent inquiries. While this reflects the issue's relevance (see chapter 3.1.2), the EMR expert also made clear that "*when it comes to the topic of disability, we reach the limits of our abilities in practice. [...]. Especially in cases where coordination law clashes with social law, it often depends on the public servant's mood on that day*" (Expert 11). According to the expert, this is due to widespread uncertainty among the civil servants about how to deal with these situations. As a result, the EMR consultants and their clients depend on the willingness to find individual solutions that potentially do not have a legal basis. Many civil servants generally show solidarity with disabled people from other EU countries, but are unwilling to take responsibility for individual arrangements.

However, even if no solution can be found in individual cases, the work of the EMR has the effect of raising awareness of the problem at various political levels, including at the EU level. At a joint conference by the EMR, the University of Maastricht, and the European Commission,²²⁵ the agenda included topics such as ‘European Citizenship and Access to Social Benefit’ and ‘sickness and invalidity’. While this is only one of many examples where the representatives from the EMR and the European Commission are in direct contact, it demonstrates that cases of cross-border mobility of disabled people have been brought to the attention of EU officials. Asked about the success rate of these exchanges, the EMR expert concluded that “*obviously, we cannot turn European social law on its head. Nevertheless, such cases are welcome at the EU Commission in order to gain an insight into practice and to identify problems.*” (ibid.)

3.2.2 Experiences by authorities responsible for disability

On the other side of the coordinating spectrum are local authorities, who have the competence to decide on disability-related aid and services. Thus, the local public servants stand in direct contact with individuals and experience the impact of their decisions. This includes personal achievements as well as sometimes dramatic situations.

The responses from these authorities or equivalent institutions²²⁶ when asked about their experiences regarding cross-border situations of disabled people have been very different. The Dutch foundation ‘Together Unlimited’ in Maastricht responded that they had no knowledge of disabled foreign people living in Maastricht, nor of Dutch citizens with disabilities who moved abroad. This foundation’s experience could result from one-sided migration paths. However, given the findings from analysis 3.1.2 regarding the scope of the issue, it seems highly unlikely. Instead, a more plausible explanation is that due to the decentralized organization in the Netherlands and the dissolution of the Public Disability Service Point of the Maastricht Municipality, affected people simply no longer have anyone to contact at the local authority.

²²⁵ MoveS seminar “Free movement of workers in the EU regions, and the EU region Meuse-Rhine (EMR) in particular: Obstacles and best practices” on September 23rd, 2019, in Maastricht

²²⁶ see Figure 28

It becomes even more unlikely that there are no cases of disabled people moving to or from Dutch Limburg in comparison with the experiences in the other EMR regions. For instance, the city of Aachen has a public coordination centre for disabled people²²⁷. It consists of three employees who offer advice on general questions regarding the participation of disabled people in society. This includes information about facilities for disabled people and questions on accessibility. Regarding inquiries in cross-border situations, the city's disabilities representative reported that in recent years, a primary concern has been the non-recognition of the disability status from Belgium and the Netherlands (expert 14). For that sake, the coordination centre has high hopes for the European Disability Card (see chapter 2.3.3).

Additionally, the public authority reported a significant lack of knowledge about the barriers when moving abroad with a disability among those who are affected by them. Instead, the civil servants regularly experience the perception by disabled citizens and their relatives that the exportability of disability-related services to Belgium or the Netherlands is a matter of course. In several cases, according to the German disability contact point, German citizens have moved to the neighbouring regions in Belgium and the Netherlands before they found out that their benefits connected to the integration of disabled people and social assistance were no longer paid by the German authorities. The legal justification for this is that, according to German social law and in accordance with the ESM, the centre of life must remain in Germany to receive disability-related benefits or services. *"This is often a big shock for disabled people, because they did not take this into account before moving abroad"* (expert 14). According to the expert, many of these people returned to Germany because losing these benefits meant too much of a burden for them.

In Liège, handling these situations seems more flexible than their German counterparts in Aachen. Individual cases can be decided in a special committee, the Municipal Advisory Commission for Disabled People. Since its foundation in 1981, the city's associations active in disability and accessibility have come together every two months. The commission's mandate is to

²²⁷ „Leitstelle „Menschen mit Behinderung“ der Stadt Aachen

analyze, on its own initiative or on behalf of local authorities, all issues relating to improving the quality of life of disabled people, their integration into society, and their leisure activities at the local and regional levels. Regarding the admission of foreigners living in Liège, the general prerequisite is that the country of origin must cover all costs. If that is the case, the advisory commission can decide on individual cases. The Walloon AViQ, in contrast, does not cover any costs for foreigners (see 3.1.1). The officials from AViQ reported a few inquiries from the Netherlands and Germany. However, since Wallonia is French-speaking, Liège has more inquiries from the French border regions of Hauts-de-France and Grand Est. This is primarily the case when there is a shortage of places in institutional settings in France.

Within the EMR, the Municipal Advisory Commission in Liège also regularly exchanges information with the East-Belgian 'Agency for Independent Living'. For the province of East Belgium, the topic has the highest significance within the EMR. Due to its small size of roughly 80.000 inhabitants, the province cannot provide a great variety of care and assistance facilities (expert 12). Generally, the province follows a strong deinstitutionalized approach, providing aid at their own living places whenever possible. For that sake, the agency has a staff force of more than 80 employees, including twelve so-called 'orientation consultants' whose task is to find adequate solutions. However, the province reaches its limits in particularly challenging cases that require around-the-clock care. According to the head of the orientation division at the Agency, "*every year we have about one to two inquiries from people with a severe disability, for whom no solution can be found within East Belgium*" (expert 12). In these cases, options to provide adequate care and assistance are sought in Germany, and occasionally in Luxembourg. These inquiries are usually made by the highest administrative level in East Belgium, the Minister for Social Affairs. According to the agency, if these individual decisions are made, they "*legally represent a gray area*" (Expert 12).

The aim is to guarantee financing abroad, ensuring the respective person can reside. However, the orientation consultants also observe a tendency that "*in recent years, it has become increasingly more difficult to find solutions abroad.*" (ibid.). The reasons for this development are, to a great extent, attributed to the

shortage of skilled social workers and caregivers, and the long waiting lists that result from this. In cases of doubt, most managers of institutionalized settings decide to admit domestic residents before taking in a Belgian citizen with an uncertain basis for refinancing the costs. This is particularly problematic for people with challenging or partly aggressive behavior who are even less likely to be admitted.

In some cases, the ESM, which foresees the responsibility for providing disability-related services at the national level, leads to sad fates in practice. The Agency for Independent Living (DSL) reported on a person from their province who suffered from the so-called 'Locked-in-Syndrome'. This syndrome refers to a condition in which the person is conscious, yet physically almost entirely paralyzed and unable to communicate through speech or movements. In many of these cases, including the East-Belgian resident, the only possibility of communicating is through eye mobility. For that reason, understanding the caregivers' language is crucial for the person to express their will. However, the DSL could not find any German-speaking institution for the person. After years of searching, the person was eventually admitted to a closed, institutional facility in French-speaking Wallonia. Not only has the person been pulled out of his social environment, but he also now lives in a place where he does not share the language with other inhabitants or the employees. Thus, they have little chance of meeting the person's needs.

3.3 Beyond the European Social Model: A best-case example

Considering these experiences by regional and local authorities, must the ESM be considered a 'hopeless case' regarding the inclusion of disabled people? To counter this view, this thesis's final chapter shows a best practice example in which (despite all odds) various actors have worked together to make cross-border mobility for a severely disabled EMR citizen possible. The aim is to gain a perspective on how the situation for disabled people living abroad could be improved and in which direction the ESM could change.

The person to whom this best-case example refers was of Belgian citizenship, living in the German-speaking province. He has been diagnosed with multiple physical and mental impairments. For that reason, the person had

comprehensive support needs, including day-to-day support and physical care needs. However, due to the small size of the German-speaking Belgian province, the support options for people with multiple severe disabilities are limited. While one residential institution for disabled people²²⁸ offers two groups for a total of 9 people with high-level support needs, not only are the places limited, but also the scope of the support. As for the person in question, his needs could not adequately be matched at the institution or anywhere else within the province.

Therefore, two options within Belgium remained: The person must either move to another residential institution in Flanders or Wallonia where he did not speak the language and could not communicate with the social workers, or he must live in a care centre for seniors with dementia, where his support needs could not be matched. For obvious reasons, neither option was in his interest nor the interest of his relatives.

In the search for suitable solutions for their client, the responsible DSL found an adequate institution, the well-established institution for severely disabled people named 'Municipal Centre for Disabled People Dr. Dormagen-Guffanti'²²⁹. However, this institution was 90 kilometres away and across the Belgian-German border in Cologne. The facility consists of seven residential groups for 48 people with severe multiple disabilities, ten of whom are diagnosed to be within the Autism spectrum. The service portfolio contains a wide range of social services, including various daily structuring measures, nursing assistance, educational opportunities, and additional therapy offers such as physiotherapy, occupational therapy, and speech therapy. With this range, the facility obtained several awards, including being named a "*best-practice example within the meaning of Article 8 of the UNCRPD, to raise awareness of disabled people and promote respect for their rights and dignity*". (Sozial-

²²⁸ House "Königin Fabiola" in Eupen

²²⁹ Found in 1913, the facility was originally named "Foundation Dr. Dormagen Cripple Home" (Stiftung Dr. Dormagen Krüppelheim). At the time, the word "cripple" did not have today's negative connotation, but was instead used to compare an impaired person to a tree that did not grow straight. The facility has a long and moving history, especially during the time of the Nazis's so-called "euthanasia-program" between 1939–1945. A dossier on the facility's 100th anniversary tells of a spectacular rescue operation, concluding that "*the question remains unanswered as to whether those living in the institution were affected by the measures of the campaign to kill 'life that was considered not worth living'*" (Sozial-Betriebe Köln, 2013, p. 36).

Betriebe Köln, 2013, p. 50). This range of services met the Belgians' needs much better than any offer within Belgium.

The facility director and her occupancy manager were interviewed about how they experienced admission of the Belgian resident (expert 14). The director herself used her EU citizen right to move and reside freely after Poland joined the EU in 2004. She has been running the facility since and has known some residents for almost 20 years. Therefore, she knows about the challenges of moving abroad from personal experience.

According to her experience, her decision to accept a Belgian residence also met resistance, because the facility has a long waiting list. Many residents' relatives know each other, including those on the facility's waiting list. There was resentment that a place was given to a foreigner, even though the place was needed for a German person (expert 14). The director explained her decision in favour of admitting the Belgian that her criteria were neither nationality, nor time spent on the waiting list, but whether the needs match the services offered by the facility, and whether the resident's personality fits into one of the residential groups. This way, the prior aim of avoiding any disruptions in the residents' communal living can be preserved. Despite the legitimate self-interest of the German relatives, no open criticism was expressed, given this reasoning.

Furthermore, the facility management was faced with legal and organizational questions. In Germany, the costs for residential settings for disabled people are borne by the respective social welfare provider and the provider of integration assistance of the region where the person grew up. However, since the person was not born in Germany, there was no legal claim for him as German social law does not apply to Belgian authorities. Additionally, the German Health Insurance, which covers costs for physical care services, would not refund costs for a person they do not insure.

For that sake, the facility director and her occupancy manager came up with the solution that although the Belgian now lived permanently in Germany, he remained registered in Belgium. That way, he could remain in the Belgian health insurance scheme while other disability-related services were reimbursed

directly by the DSL. Conversely, the agency achieved an individual agreement with the province's minister for social affairs. German institutions such as the regional social welfare authority (LVR) or other local authorities, such as the city of Cologne, were informed, but did not need to be involved.

However, this solution had a few disadvantages. Since there has been neither experience nor legal entitlement, the Belgian's admission to the facility was solely based on the facility management's trust that the Belgian authorities would keep their word and remunerate the services accordingly. At the time of the interview, the occupancy manager concluded that the remuneration had been unproblematic (experts 12 and 14).

The uncertainty regarding the agreement also affected the Belgian resident. Because the reimbursement was solely based on an agreement between the DSL and the social minister, it has been dependent on her term in office. If not re-elected, there was no guarantee that the next minister would continue this agreement.

Occasionally, the experts reported that differences in the definition of disability between Belgium and Germany affected the daily business at the facility (expert 14). Since the director has been running the facility since 2004, she has also been responsible for implementing the UNCRPD in daily practice. Part of this implementation has been that *"disability is no longer a medical problem, but a social one"*. [...]. *For the work in the municipal center for the disabled, this means not defining the residents as 'carriers of a deficit'. Rather, an attempt is made to determine the 'abilities and skills' and, as a result, to determine an individual's need for support."* (Sozial-Betriebe Köln, 2013, p. 49).

What reads like a rather abstract lip service has, in fact, direct consequences for the residents, because the individual's need for support defines the entitlements for social services that may be reimbursed by the health insurance and/or the local authorities. However, since Belgium follows a medical approach to disability, there are differences in the services covered by the Belgian health insurance company. According to the facility director, this led to situations in which Belgian and German residents have been treated differently regarding

the provision of services because there has been a lack of financing by the Belgian health insurance company (expert 14).

A third challenge was communicating with the person's legal representative. Unlike the German residents, whose representatives mainly live within the city of Cologne, the Belgian representative remained in Belgium. In urgent situations or when there is a problem between the resident and the social workers, he is less accessible for short-term arrangements. On this page, there is a leap of faith in the facility management to make the right decision.

Despite these challenges, the interviewed experts concluded that the admission of the Belgian resident to their facility was a success story (experts 12 and 14). Even further, the occupancy manager reported that the cooperation within Germany occasionally has been more complicated than with the Belgian authorities. For example, she reported a request from a resident who wanted to move from a Bavarian province to Cologne. However, the Bavarian district responsible for covering the costs would not agree to the temporary reimbursement of costs but referred to a processing time of 4 months or longer. The manager decided to take in someone else since the facility cannot reserve a place for that long.

Coincidentally, precisely at the time, the Belgian DSL sent a second request to admit another Belgian person.²³⁰ As in the first instance, the reason for the request was the insufficient support options in the German-speaking Belgian province. However, unlike the first time, the person in question was bilingual (German/French). Thus, admission to a facility in French-speaking Wallonia would also have been an option, and the necessity to move abroad would have been less urgent. Nevertheless, due to the positive experiences on both sides, the foundation Dr. Dormagen has been the preferred choice.

Eventually, a Belgian resident moved to the German facility in Cologne for the second time because international communication with the Belgian authorities proved less complicated than domestic communication with regional authorities in other German federal states.

²³⁰ By the time of the interview, the first Belgian resident has passed away.

This best-case example shows that if the will is there, even in challenging cases, cross-border mobility for disabled people is possible. However, even in this best-case example, ‘freedom of movement’ really is the “*freedom to take or not to take the only available option*” (Expert 13).

The thesis’s final chapter aimed to identify the possibilities and limits of these cooperations. The EMR has established forms of cooperating in permanent panels and working groups on various issues. However, the provision of disability-related benefits and services is none of them, even though the representatives of the EMR and its consulting body often receive inquiries of this kind from EMR citizens. The EMR’s experiences match with reports from local civil servants. Like the EMR, local authorities experience these cases regularly. However, in many of these cases, they also have no answer or feel uncertain about the legal framework. On the contrary, those affected are often surprised when finding out that their benefits are not covered when moving abroad. Eventually, many move back to their country of origin. According to local experts, the reactions reflect a common understanding among disabled people that freedom of movement applies to all EU citizens, notwithstanding the reception of disability-related benefits or services. For that sake, the EMR and local authorities have high hopes for the success of the European Disability Card to serve as a legal basis.

Despite legal limitations, the cooperation of EMR regions directly influences EU disability policies. The EMR representatives, who expressed their self-conception as intermediaries between (EU) politics and practical implementation, have well-established channels with the EU institutions in Brussels and Strasbourg. Therefore, their experiences, including the frequent inquiries by disabled EMR citizens, are important reference points in drafting EU policies.

Coordination between local authorities and other stakeholders exists at various levels, facing challenges and opportunities. However, without legal certainty, the success of coordinative efforts greatly depends on the goodwill and individual capacities of the involved stakeholders. The absence of a clear legal basis is

both a blessing and a curse. On the one hand, it causes legal uncertainty. On the other hand, however, coordination on financial matters seems less problematic because agreements are always made individually. According to the experts, the bigger challenge is the lack of capacity due to staff shortages among social workers. Thus, local civil servants tend to ensure their communal mandate to provide social services to their domestic citizens first, before considering the admission of EU foreigners. Therefore, the success of bilateral cooperation outside the EU jurisdiction varies greatly.

Within the EMR, coordination with other local authorities is particularly crucial for the German-speaking community in East Belgium. Due to the provinces' small size, the local range of social services is limited and sometimes insufficient. In a particularly saddening example of failed cooperation, a German-speaking Belgian with locked-in syndrome was brought to a French-speaking facility in Wallonia. Due to his nationality, he was not admitted to any adequate institution in Germany.

In a best-case example, an individual agreement based on trust was made between a facility in Cologne and the Belgian authority. Since the agreement was fulfilled, the institution approved a second request under similar conditions. The prerequisite was, however, that the two Belgians must remain registered in Belgium, and the Belgian state bears the costs. Thus, they were able to move abroad – but not to reside.

Conclusion

The guiding question throughout this thesis has been whether disability may be a driving force in moving the European Social Model from an accumulation of independent national social systems towards an integrated European system based on mutual solidarity. Based on the findings of this thesis, the answer to this question is affirmative.

However, the influencing factor is not simply disability itself but the change that the concept of disability has undergone. In other words, while disability concepts and local, regional, and national systems have been changing (and still change) significantly from a charity-based understanding to a rights-based approach (see e.g. Barnes, 2018; Degener, 2016; Anastasiou et. al., 2013), the European Social Model has not yet gone through the same process. The increasing significance of the social model of disability widens the gap between the self-perception of disabled EU citizens and the partly outdated EU social law. The ‘inventor’ of the social model of disability has famously quoted that *“we do have a hammer in the disabled people’s movement and, if properly used, the social model of disability could become the means of achieving justice and freedom for disabled people”* (Oliver, 2009, p. 57). Indeed, while it has not yet caused a fundamental reform of the ESM, this thesis’s evaluations have shown that the increasing gap has already impacted key policy fields essential to disability and social security.

The development in understanding disability as a social circumstance rather than a medical condition is ‘button-up’, from grassroots organizations to providers to local systems. Disability organizations work hard to have the UNCRPD’s definition of disability²³¹ recognized at all administrative and executive levels (experts 6,7, 10). The EU Commission, in contrast, while highlighting the UNCRPD’s significance on the one hand, has also stated that *“the definition of disability depends on its intended use: non-discrimination laws may be based on different criteria from those used to determine eligibility for*

²³¹ *“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”* i.a. Website European Commission, DG EMPL

state benefits.”²³² Until now, this inconsistency appears to be a loophole in upholding the ESM's status quo. It comes at the expense of a disadvantageous unequal treatment of disabled people in cases where exporting disability-related entitlements to another EU country would be necessary.

The process of emphasizing the rights of disabled people, however, is still ongoing. Because of that, the tension between the inconsistent definition on the EU level and disabled people's rights as European citizens continues to grow. The term 'people with disabilities' itself, implying that disability is a medical characteristic, is increasingly questioned. Additionally, multiple experts (6,7,8,9, and 10) expressed dissatisfaction with the term 'benefits' when referring to disability-related services or cash transfers. Instead, the word 'entitlements' has been requested.

At the beginning of this thesis, it has also been asked whether regarding disability *“the stigmatization and separation of deviants have a stabilizing function for the social system (...).”* (Cloerkes, 2014), and whether combating stigmatization has a destabilizing effect on the respective social system. To answer this question, disability lobby groups with the intention and the power to counter biases among policymakers have been interviewed (experts 7, 8, 9, and 10). On the European level, numerous disability lobby groups have organized themselves under the umbrella organization 'European Disability Forum'. All experts from these disability lobby groups confirmed that fighting these prejudices among policymakers is a top priority of their work. Among others, its key demands have been freedom of movement, the enhancement of citizens' rights, and the exportability of disability-related entitlements. Their work has indeed proven to be effective: Improving cross-border mobility is not an occasional appearance on the EU policy agenda, but it has been named a goal in recent European disability strategies. Furthermore, the analysis of European disability policy frameworks since 2004 indicates a clear development towards a rights-based approach. Unlike its predecessors, the most recent framework until 2030 has even been named 'EU Agenda for Disability Rights'.

²³² Commission Staff Working SEC (2010) 1323 final, p. 4

However, a gap remains between the intentions of legally non-binding policy frameworks and secondary law based on which a legal claim could be asserted. There are two reasons for this gap: First, resulting from the traditional medical understanding of disability, disability policies tend to be integrated into a broader spectrum of social policy. This so-called 'mainstreaming' of disability policies is at least partly intentional, yet occasionally it comes at the expense of targeted policy measures. Second, these legal claims lay in the tension field of citizens' rights on the one hand and member states' competence to organize their social systems on the other hand (as described e.g. by Golynger, 2020). Remarkably, the key points of dispute about shifting social competences from the national to the EU level do not concern disability.

This is particularly evident in the development of social security coordination. Since 2016, attempts have been made to reform the existing legislation, yet an agreement between the EU Parliament and the Council appears to be out of reach. Experts from both institutions confirmed that a compromise was found regarding the social security of disabled people in cross-border situations (experts 4 and 5). However, due to the mainstreaming of disability policy in the general field of welfare, disability-related social security benefits fell victim to the politically more sensitive area of unemployment. This is remarkable in the context of this thesis's research question because it demonstrates the general willingness to partly shift competences in the social policies to strengthen disabled people's rights as EU citizens.

The general confusion about defining disability is also noticeable in other policy areas, particularly regarding developing anti-discriminatory policy measures. Like the coordination of social systems, there is a political consensus that European anti-discrimination law must also be reformed. However, a draft law for a so-called horizontal non-discrimination directive from 2008 has been stuck for almost two decades. According to an expert from the Council's working group on this dossier, the central issue has been (and still is) the lack of a mutual approach to disability (expert 5). On the one hand, from the medical perspective, the severity of discrimination could be measured proportionally to the degree of disability. From a social perspective, on the contrary, disability could not even be the ground of discrimination, but it is the result. Thus,

concerns about the potential impact of a horizontal non-discrimination directive remain due to the lack of a common understanding. Instead of falling victim to other areas, in this case, disability has been the cause of a blockade within the Council led by the German delegation. Since the directive also covers various grounds of discrimination, such as gender, age, or cultural origin, the adverse effects of this blockage are far-reaching. This raises the question of whether the mainstreaming of disability can be a sufficient approach or whether anti-discrimination law should be accompanied by disability-specific legislation to protect those who experience disability due to an inaccessible environment from further disadvantages.

However, the most substantial barrier to moving abroad appears to be access to social services of general interest (SSGI), including support services for disabled people. Several experts (3, 6, 7, 9, 10, 11, 12, 13) reported that support services are often insufficient or inaccessible in cross-border situations. One reason is the considerable differences in the quality of assistance services, as shown by a special report from the European Court of Auditors. Those needing assistance can often not rely on adequate support when moving abroad. To counter this barrier to free movement, it must be recognized that organizing disability-related services on the local level only may lead to cases of dependency and deficiency. Instead, European quality standards for SSGI and coordination methods on multiple levels (as described e.g. by Kazepov, 2010), on which disabled people can rely when moving to another EU country, are needed.

Another reason is the predominant assumption among policymakers of an 'unequal relationship' between providers and receivers of social services. The European Commission has manifested this inequality in the context of implementing the Lisbon Treaty. This understanding of social service receivers as supplicants rather than customers is a crucial difference compared to other services and evidence of the growing gap between the self-perception of disabled EU citizens and the ESM. Essentially, this downgrading of service receivers prevents SSGI (including assistance services for disabled people) from further integration.

Nevertheless, the work by European disability lobby groups such as the EDF has shown results. The introduction of the European Disability Card marks a milestone in developing a rights-based European disability system. Its main achievement, the mutual recognition of disability status when traveling abroad, has the potential to truly facilitate cross-border mobility. Although important demands from stakeholders, such as the exportability of benefit claims, have not been implemented, the path unequivocally points toward increased cooperation between disability-related social systems. In that context, the chairwoman of the disability intergroup in the European Parliament, MEP Katrin Langensiepen, assesses that “*the path leads towards a European social union*” (Expert 3, 2023).

Local civil servants and practitioners expressed high hopes for the upcoming implementation of the European Disability Card (Experts 11, 12, and 13). Their experiences have shown that, to date, solutions have been found on a case-by-case basis and often without a legal basis. This requires the goodwill of individual persons, who in reverse might have to stretch their mandates against the resistance of others. Interestingly, in the case of the EMR, the boundaries of competence do not align with national borders, but rather with regional jurisdictions. Practical cases have shown significant challenges when moving domestically, for example, from Flanders to Wallonia or from Bavaria to North Rhine-Westphalia. Thus, the further rights-based thinking regarding disability is implemented in EU law, the more it will affect how member states organise their social systems regarding disability.

To summarize, it has been established that the rights of disabled people significantly impact important areas of social policy. It has also been established that this influence, concerning freedom of movement, points towards further integration. What does this mean for 'challenging the European Social Model'? The answer depends on through which lens the ESM is seen²³³. Suppose the ESM is reduced to a necessity to respond to economic challenges from increasing globalization (e.g., Vaughan-Whitehead, 2003). In that case, the rights of disabled people are indeed only a small economic factor. Likewise, if

²³³ See Framework: The European Social Model (ESM)

the ESM is seen as a tool to legitimize political action (e.g., Jespsen; Pascual, 2005), the honest answer is that disability is not (and never has been) a sexy topic for politicians. Most voters do not want to be confronted with disability, because the association with suffering is very much present. Thus, strengthening disability rights is not suitable for legitimizing actions. On the contrary, a sufficient goal for most politicians is not to attract negative attention when dealing with disability. However, the more the association with suffering is challenged, the more disability is brought to the policy agenda.

However, suppose the ESM is seen as a common goal or used to visualize an ideal situation of the common European objective to achieve social protection and equality for all EU citizens (e.g. Scharpf, 2002; Esping-Andersen; 1999; Ferrera; 2005). In that case, including disabled people in all areas of the European integration process is not a bonus feature but a basic requirement. Demanding fundamental rights as EU citizens thus moves the discussion from 'if' different rules apply when a disability is diagnosed to 'how' equality can be achieved when disability occurs due to a discriminatory circumstance.

Regardless of the theory through which the ESM is seen, the right of disabled people to move and reside freely within the EU challenges the ESM's current basis: the independence of national social systems.

Abbreviations

ANED	Academic Network of European Disability Experts
AViQ	Walloon Agency for Quality of Living ('L'Agence pour une Vie de Qualité')
AWIPH	Walloon Agency for the Integration of People with Disabilities (‘Agence Wallonne pour l'Intégration des Personnes Handicapées’)
BTHG	German Federal Law for Inclusion (‘Bundesteilhabegesetz’)
CFR	Charter of Fundamental Rights
CoR	Committee of Regions
DDA	Disability Discrimination Act
DG	Directorate-General
DISCIT	Research Project “Making Persons with Disabilities Full Citizens - New Knowledge for an Inclusive and Sustainable European Social Model”
DOTCOM	Disability Online Tool of the Commission
DPOD	Disabled People’s Organization Denmark
DSL	Agency for Independent Living in East Belgium (‘Dienststelle für selbstbestimmtes Leben in Ostbelgien’)
EASPD	European Association of Service Providers for Persons with Disabilities
ECA	European Court of Auditors
ECJ	European Court of Justice
EDF	European Disability Forum
EDS	European Disability Strategy 2010-2020
EESC	European Economic and Social Committee
EMR	Euregio Meuse-Rhine
ENIL	European Network on Independent Living
EP	European Parliament
EPSR	European Pillar of Social Rights
ESM	European Social Model
EU	European Union
FPS	Belgian Federal Public Service for Social Security
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
LSHPD	People with long-standing health problems or disability
LVR	Regional Association of the Rhineland (‘Landschaftsverband Rheinland’)

How citizens' rights challenge the European Social Model

MEP	Member of the European Parliament
MHE	Mental Health Europe
NCDP	National Confederation of Disabled People of Greece
NIHDI	Belgian State Institute for Health and Disability Insurance
OMC	Open Method of Coordination
PHARE	Brussels Service for Disabled Persons Seeking Autonomy (‘Service bruxellois Personne Handicapée Autonomie Recherchée’)
SOC	EESC’s Section for Employment, Social Affairs and Citizenship
SQWP	Social Questions Working Party of the Council of the European Union
SRPD	Strategy for the Rights of Persons with Disabilities 2021-2030
SSGI	Social Service of General Interest
SWP	German Association for Economy and Policy (‘Stiftung Wissenschaft und Politik’)
TFEU	Treaty of the Functioning of the European Union
UMV	Dutch Employee Insurance Implementation Agency (‘Uitvoeringsinstituut Werknemersverzekeringen’)
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VAPH	Flemish Agency for Persons with Disabilities (‘Vlaamse Agentschap voor Personen met een Handicap’)
VWS	Dutch Ministry of Health, Welfare and Sport (,Ministerie van Volksgezondheid, Welzijn en Sport’)
WHO	World Health Organisation
WMO	Dutch Social Support Act (,Wet maatschappelijke ondersteuning’)

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