

Multiple Sclerosis and the Labour Market in the Nordic Countries

An exploratory literature review



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– An exploratory literature review

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Preface

This literature review focuses on people with multiple sclerosis (MS) and their labour market outcomes in the Nordic countries. In the report, we gather the existing literature in this field and compare the outcomes across the five Nordic countries.

The literature study is conducted by analyst Laura Skifter Andersen and senior analyst Christian Højgaard Mikkelsen from VIVE.

As a part of this study, MS Societies from each of the Nordic countries have contributed to the study by conducting the literature search in their own respective language. The MS Societies also offered a summary of available labour market schemes and pension and retirement arrangements for individuals with multiple sclerosis in their own country. We would like to thank each of the MS Societies for their contributions. Without their engagement, this study would not have been possible.

The report has been reviewed by a highly qualified reviewer. We would like to thank the reviewer for good and constructive comments.

The report is commissioned by the Nordic MS Council.

Lisbeth Pedersen

Head of Research for VIVE Work and Late Life

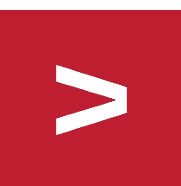


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Key Findings

Multiple sclerosis (MS) is a chronic, progressive disease that impacts the central nervous system and functionality and thereby the ability to engage in the labour market. Therefore, people with MS have lower labour market attachment than the rest of the population.

MS is more common in the Nordic countries compared to the rest of the world. However, there is currently no overview of labour market attachment for people with MS across the Nordic countries. This report can be used by policymakers, interest organisations and researchers who want to know more about labour market attachment and working life of people with MS.

The report is based on knowledge from studies that focus on various measures of labour market participation for people with MS. The main themes of the report are labour market attachment, disability pension and sickness absence, income and productivity loss, and working life of people with MS.

Labour market attachment

Overall, the labour market attachment is lower for people with MS than for the rest of the population in the Nordic countries. 12 of the included studies report employment rates for people with MS. In 6 out of these studies across the Nordic countries, the reported employment rate is between 40% and 50%. 4 studies report rates between 30% and 40%, while 2 studies indicate employment rates exceeding 50%. The studies vary in for example methodology, data collection years and the age ranges of participants, but all studies show that the employment rates are significantly lower among people with MS than among the rest of the population.

Several studies find that employment rates tend to decrease with age and with severity of the disease. Across studies, the findings are that relapsing-remitting MS (RRMS) patients have the highest employment rates while patients with secondary progressive MS (SPMS) have the lowest. Also, higher levels of education are associated with higher employment rates.

Disability pension and sickness absence

Several studies conducted in Denmark, Finland and Sweden consistently find that the risk of disability pension and sickness absence increases with time after MS onset or with age. Accordingly, some studies reported that significant differences in sick leave or employment rates between people with and without MS can be found several years prior to MS diagnosis.

Other studies show that the risk of sickness absence and disability pension does not only increase as MS progresses. A few studies from Sweden find that some people with MS have the highest number of sickness absence or disability pension days around the time of diagnosis. This indicates that people with MS can re-enter into the labour market after some time away from work around the time of diagnosis.

Time from MS onset or from diagnosis to disability pension has been measured in several studies across the Nordic countries. The average time from MS onset to disability pension is calculated to be 13.5 years in Finland. The mean age of receiving disability pension among people with MS is calculated to be between 43 years (in Sweden) and 45 years (in Finland). A Danish study finds that earlier treatment delays the risk of disability pension. 10 years after onset, the risk of receiving a disability pension was 10% for people with MS who began treatment within 1 year, while the risk was 23% for people who started treatment within 4-8 years. This is in line with a Finnish study showing that the median time from diagnosis to disability pension has increased over the years, likely due to the evolved treatments such as disease-modifying therapies (DMTs) and rehabilitation.

The studies included in this literature review identify different characteristics that increase the risk of disability pension and sickness absence. Female gender, engagement in physical work, efferent onset symptoms and delayed treatment for RRMS are all characteristics that are associated with higher sickness absence and risk of disability pension.

Income and productivity losses

Since the employment rate is lower for people with MS, the income is also lower for this group compared to the rest of the population. However, some studies find that people with MS experience an income loss after diagnosis, while other studies find that income for people with MS is stable after diagnosis, while people without MS experience an increase in income.

Several studies investigate the total economic costs in society due to MS. The productivity losses due to MS are estimated to be between 44% (in Finland) and 61% (in Norway). One of the studies finds that the productivity losses are not only due to decreased working ability among people with MS: In Finland, informal care provided by family and friends accounts for 13% of the total economic costs.

Working life and symptoms affecting working life

Several studies find that especially 'invisible symptoms' such as fatigue and cognitive difficulties impact working life of people with MS the most. As the modern labour market becomes more and more cognitively demanding, even mild cognitive symptoms can have a large impact on working life and working ability of people with MS.

One of the main concerns of people with MS in employment are the uncertainty related to disease progression and how this will affect their job situation over time. Therefore, they consider flexibility and open communication with employers very important.

Knowledge gaps

Based on this literature review, we have outlined some tentative knowledge gaps.

There are very few studies identified concerning job types or career changes among people with MS. We have found no research on working conditions, alternative employment arrangements and initiatives for retaining people with MS in the workforce. Accordingly, no effect studies evaluating the effectiveness of initiatives designed to maintain work participation for people with MS were identified. Additionally, while some qualitative studies touch on employer perceptions, no in-depth studies explore how these perceptions affect job barriers and opportunities for MS patients.

We found no research papers concerning MS and the labour market in Iceland and no cross-country comparisons within the Nordic region despite high MS prevalence. Finally, as there are rapid advancements in the treatment of MS, new research is essential to demonstrate how this affects labour market outcomes.

Facts about the literature review

This report is based on a literature search.

The literature search is planned and coordinated by VIVE but conducted by MS Societies from Denmark, Finland, Iceland, Norway and Sweden. The search consists of an exploratory literature search and snowball search in each of the Nordic languages and English.

Submitted literature is screened, examined and reported by VIVE.

In total, 28 relevant publications were identified: 12 from Denmark, 4 from Finland, 0 from Iceland, 4 from Norway and 8 from Sweden.

We have included studies from the Nordic countries that focus on various keywords related to the labour market. We have primarily included quantitative studies.

> Report

1 Introduction

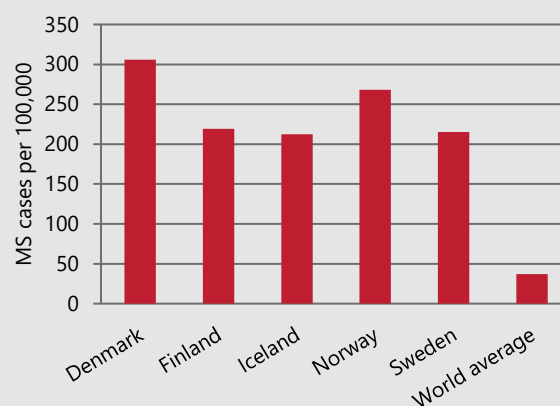
Multiple sclerosis (MS) is a chronic and progressive disease, affecting the central nervous system and both gradually and periodically reducing functionality, including the ability to participate in the labour market. Literature shows that MS has negative effects on a person's working life, as work participation decreases with the progression of the disease (Kjellberg & Ibsen 2020). Individuals with MS have significantly lower work participation rates and a higher likelihood of being on sickness absence, in flexible employment or on disability pension compared to a comparable group without MS (Kjellberg & Ibsen 2020).

There is a high overrepresentation of MS in the Nordic countries compared to the rest of the world. It is estimated that approximately 2.9 million people worldwide are living with MS in 2023, which corresponds to a prevalence of 37 people with MS per 100,000 inhabitants (MS International Federation 2023). For the five Nordic countries that we focus on in this report, that is, Denmark, Finland, Iceland, Norway and Sweden, the prevalence is over 200 per 100,000 inhabitants, see Figure 1.1. Several studies have shown that living in countries at higher geographical latitudes is associated with a greater risk of developing MS (MS International Federation 2020).

To have a job is important for some people's identity. Having a job creates a meaningful and structured daily life and promotes social relationships. To lose a job or to have your working capacity limited can therefore be experienced as a significant loss and can result in a crisis for the individual who experiences this. This is especially the case for people who lose their job in an early age due to a chronic disease (Martin & Mehlsen 2020). Furthermore, having a job is the foundation for good financial conditions, which are also beneficial for one's quality of life.

Figure 1.1 Prevalence of MS in the Nordic countries and in the world

Prevalence is measured as cases per 100,000 inhabitants.



Source: (MS International Federation 2023; Magyari, Pontieri & Joensen 2023; Aarseth et al. 2024)

Most people with MS are diagnosed between the ages of 20 and 40 years, a time when people are typically working or undergoing education. Accordingly, the disease can affect the financial security for people with MS. Simultaneously, reduced working capacity or job opportunities can impact mental and physical health (Martin & Mehlsen 2020).

Although the prevalence of MS is high in the Nordic countries and labour market attachment is important on both individual and societal level, there is no existing literature that compares labour market outcomes across these countries. The primary objective of this report is to gather information and offer an overview of knowledge about MS and labour market outcomes in the Nordic countries.

This report contributes by identifying areas studied in each country and indicates where the existing knowledge falls short. Furthermore, the comparison of initiatives in the Nordic countries contributes with insights into differences and similarities in both labour market participation and employment initiatives for people with MS. This might provide a basis for shared learning and inspiration across countries. The report will concentrate on four key areas:

- Labour market attachment
- Sickness absence and disability pension
- Income and productivity losses
- Working life and symptoms affecting working life

These four areas have been identified from the gathered literature. For each of the countries we will present the results regarding these themes.

The report is targeted at policymakers and interest organisations seeking knowledge about labour market conditions for people with MS. Additionally, the report can be used by researchers who want an overview of the available knowledge in this area in the Nordic countries.

The overall project is planned and facilitated by VIVE, and the literature search has been conducted by the MS Societies. Each of the Nordic MS Societies have conducted an explorative literature search concerning multiple sclerosis and the labour market covering publications from their own country. The searches have been conducted in English and the Nordic languages. Searching techniques include keyword search and snowballing. It has been up to the individual MS Societies how they conducted their search. As some of the MS Societies are already aware of relevant publications, due to previous collaborations or networks, these publications are included in the knowledge gathering as well.

There may be variations in the depth and scope of the searches across countries. Therefore, the literature search cannot be considered exhaustive. It might not cover all aspects of multiple sclerosis and the labour market, as some relevant publications may not be included. The individual societies may, however, be aware of parts of especially the grey literature and publications written in their own language which can provide valuable information.

1.1 What is multiple sclerosis

The development and the symptoms of MS are highly diverse, depending on clinical phenotype and severity. Some people with MS experience rapidly accumulating symptoms and extreme limitations in everyday life, while others are less affected by the disease (Landfeldt et al. 2018; Scleroseforeningen 2022). Symptoms vary and may include fatigue, weakness, cognitive and sensory changes, pain, spasticity, impaired balance and coordination, visual disturbances, tremor and speech disturbances among other things (Maltseva 2018). Accordingly, MS is a condition that impacts everyday life, including working life and ability to work (Landfeldt et al. 2018).

MS can be either relapsing-remitting or progressive. Relapsing-remitting MS (RRMS) is characterised by periods of relapses or new symptoms followed by full or partial recovery. RRMS is the most common type of MS and is especially frequent among younger persons. For most patients with RRMS, the disease develops into a progressive MS, called secondary progressive MS (SPMS). Progressive MS is characterised by a gradual worsening of disease symptoms over time. Primary progressive MS (PPMS) is if no clinical symptoms of the disease have been previously reported before disease onset. Progressive MS is more widespread among older patients (Castelo-Branco et al. 2019; Skogli et al. 2023).

The onset of MS is defined as the first time a person notes a change in the usual health status with symptoms which can be related directly to MS (Gambert 2013).

1.2 Extent of MS in the Nordic countries

As we saw from Figure 1.1, Denmark has a prevalence of 306 people with MS per 100,000, the second-highest prevalence in the world¹. This corresponds to approximately 18,600 cases in total, see Table 1.1. Norway ranks sixth with a prevalence of 268 people with MS per 100,000 or approximately 14,600 cases in the population.

¹ San Marino has the highest prevalence of MS in the world with 337 people per 100,000 affected. However, as San Marino has a population of only 33,864, this prevalence rate is associated with a high degree of uncertainty (Rudbæk 2024).

Finland has 219 people with MS per 100,000 (12,600 cases in total). Sweden and Iceland have 215 and 212 people with MS per 100,000 (22,000 and approximately 800 cases in total), respectively (MS International Federation, 2023).

Most people with MS, around 70%, in the Nordic countries are women. This number ranges from 67% in Norway to 73% in Iceland.

The mean age of onset is 40 years in Finland which is the highest among the Nordic countries. Iceland have the lowest mean age of onset at 36 years.

Table 1.1 Number of MS cases, percentage of individuals with MS who are women and mean age of onset in the Nordic countries

	Number of MS cases	Percent of MS cases, women	Mean age of onset
Denmark	18,616	69	37
Finland	12,633	72	40
Iceland	813	73	36
Norway	14,672	67	39
Sweden	22,209	70	38

Note: Data from Finland and Iceland are from 2024, Denmark and Norway from 2023 and Sweden from 2022.

Source: Magyari, Pontieri & Joensen (2023); Neurorekisteri (2024); MS International Federation (2023); Aarseth et al. (2024)

In Denmark, the median Expanded Disability Status Scale (EDSS)² score for the working-age population with MS is 2, ranging from 1 among the youngest age group (18-24 years) to 3.5 for the oldest age group (55-64 years) (Wandall-Holm, Andersen et al. 2022).

In Norway, individuals aged 20-29 have a mean score of 1.4, indicating mild disability, while those aged 70 or older have an average score of 5.1, indicating moderate disability. Overall, 65% of individuals with MS have mild disability, 15% experience no disability, 13% experience moderate disability and 8% have severe disability (Skogli et al. 2023).

In Finland, there are considerable geographical variation in the prevalence of MS. MS is particularly prevalent in the western part of the country (Ruutiainen et al. 2016).

² Expanded Disability Status Scale is a method for measuring the severity of MS. It is widely used in evaluating individuals with MS. The scale ranges from 0 to 10 (Multiple Sclerosis Trust 2020).

1.3 Reading guide

The report presents information about and publications from each of the Nordic countries in separate chapters. In each chapter, we initially describe the employment initiatives that exist and are aimed at MS patients in each of the Nordic countries. These descriptions are based on information provided by each of the individual MS Societies; accordingly, they include initiatives considered relevant by the MS Societies.

The studies are all from different countries and thus different institutional frameworks. Additionally, they have varying thematic focuses and methodologies, and the data were collected in different years. Therefore, the results are not necessarily comparable across studies and countries. Moreover, the focus may often be on subgroups of MS patients, meaning the results of a study are not necessarily representative of all individuals with MS.

In Chapter 2, we have compared the results for all the countries with these caveats in mind. In Chapter 3-7 we have categorised the studies for each country according to the four themes. Chapter 8 contains the methodology section.

2 Comparison and overview

In this chapter, we will discuss the findings from included publications and compare the results from the different Nordic countries. This chapter will encompass the four themes we have identified in the included literature:

1. Labour market attachment
2. Disability pension and sickness absence
3. Income and productivity losses
4. Working life and symptoms affecting working life

The analysis is based on findings from all 28 publications included in this literature review, see Chapter 8 for inclusion criteria. Finally, we will identify and discuss relevant knowledge gaps concerning MS and labour market participation in the Nordic context.

In Table 2.1, the number of included publications is sorted by country and theme. A study may address multiple themes. In the table, the studies are categorised according to their primary focus. Most studies (12 out of 28) focus on disability pension and sickness absence. 8 focus on income and productivity loss. 5 focus on working life and symptoms affecting working life, while 4 focus on labour market attachment.

Table 2.1 Number of included publications by country and theme

Country	Labour market attachment	Disability pension and sickness absence	Income and productivity loss	Working life
Denmark	1	5	2	4
Finland	0	1	2	1
Iceland	0	0	0	0
Norway	2	0	2	0
Sweden	1	5	2	0
<i>In total</i>	4	11	8	5

In 2020, the MS International Federation published a report mapping the prevalence of MS around the world with epidemiological data. The data in the report are from 2020, whereas the most recent previous version dates back to 2013. The authors state that since 2013 there have been improvements in diagnose guidelines globally. This means that many more individuals are diagnosed with MS earlier, which also means

an increased total number of MS cases. When MS is diagnosed earlier, it is easier to intervene earlier with DMTs which can help delay the progression of the disease. In turn, this also helps people with MS maintain their labour market attachment.

This shows that the diagnostic tools and treatment of MS are rapidly advancing. The oldest study included in this literature review is from 2010, Pflieger, Flachs and Koch-Henriksen, which, in a scientific literature context, is quite recent (However, the data used for this study are from 1980-1989, which in this setting is relatively old). The rapid development in MS treatment is therefore important to consider, especially when interpreting the older studies.

2.1 Labour market attachment

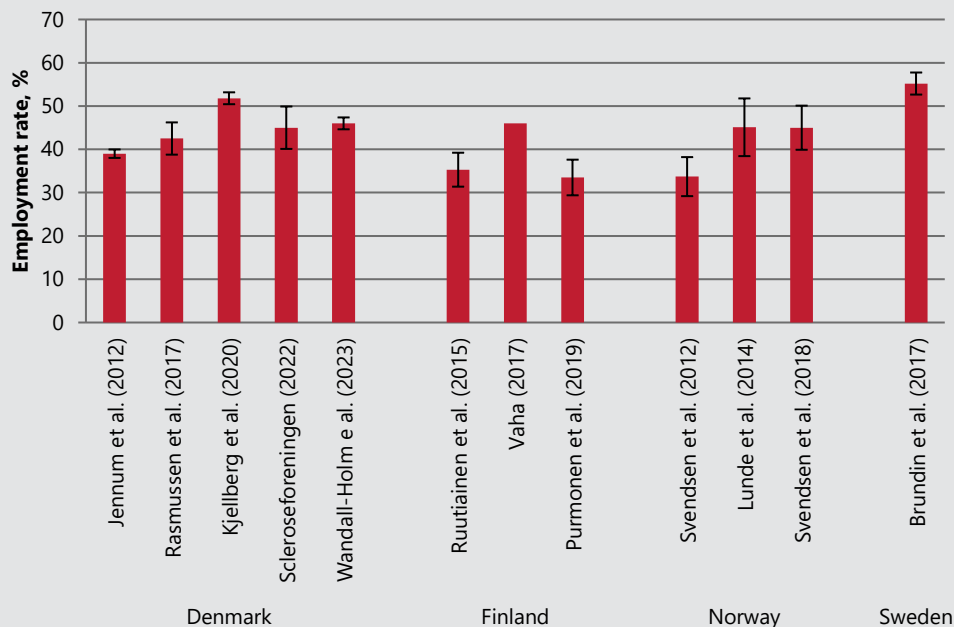
12 of the reviewed publications provide data on employment rates, with contributions from 5 studies in Denmark, 3 in Finland, 3 in Norway and 1 in Sweden.

In Figure 2.1, we present an overview of employment rates across these countries and studies. It is important to note that these studies vary in methodology, data collection years and the age ranges of participants, among other factors. Therefore, the employment rates are not necessarily comparable across studies. However, Figure 2.1 offers a general overview of labour market participation among people with MS in the Nordic countries.

In 6 out of the 12 studies, the reported employment rate is between 40% and 50%. 4 studies report rates between 30% and 40%, while 2 studies indicate employment rates exceeding 50%. In all of the Nordic countries, the employment rate of people with MS is significantly lower than for the rest of the population. Since the employment rates in most studies are largely of the same magnitude across studies and countries, we cannot claim that the employment rate is higher in one country or other.

Figure 2.1 Employment rate for people with MS in the Nordic countries

Employment rates and confidence intervals¹ in the included papers that show employment rates. Grouped by country and sorted by publication year.



Note: Employment rates includes full time employment, part time employment and flex job. See Table 2.2 for distribution of these types of employment.

Studies vary in methodology, data collection years and the age ranges of participants, among other factors. Therefore, the employment rates are not necessarily comparable across studies.

For calculation of 95% confidence intervals, see section 8.4.

In Table 2.2, we show some further characteristics of the studies included in Figure 2.1. These characteristics include age of examination, year of data collection, fraction of full- and part-time employment and type of data. This table gives an overview of some of the similarities and differences between the studies to help understand how comparable the studies are.

We see that in the four studies in Figure 2.1 where the employment rate is below 40%, the age group of examination is all ages or from 21-88 years. This means that the total population in the studies is larger than the population in the working age which, all else being equal, will lower the employment rate relative to the studies that only examine the population in the working age.

Table 2.2 Overview of study characteristics for papers that show employment rates

	Study	Age of examination	Year of data collection	Full/part time, flex job	Type of data
Denmark	Jennum <i>et al.</i> (2012)	All ages (8% over 70 and 1% under 20)	1998-2006	-	Administrative data
	Kjellberg & Ibsen (2020)	16-64	2007-2016	39% ordinary employment, 13% in flex job	Administrative data
	Rasmussen <i>et al.</i> (2017)	Working age	2015	15% full time, 27,1% part time	Survey
	Scleroseforeningen (2022)	20+	2022	17% full time, 2% part time, 24% flex job	Survey
	Wandall-Holm <i>et al.</i> (2023)	50-64	2021	21% full time, 21% part time	Administrative data
Finland	Ruutiainen <i>et al.</i> (2016)	21-88	2014	-	Survey
	Vaha (2017)	18-64	-	38% full time, 8% part time	Survey
	Purmonen <i>et al.</i> (2020)	21-88	2015	22% full time, 11% part time	Survey
Norway	Svendsen <i>et al.</i> (2012)	All ages	2002	-	Survey
	Lunde <i>et al.</i> (2014)	20-66	2010	19% full time, 26% part time	Survey
	Svendsen <i>et al.</i> (2018)	All ages	2013	31% full time, 14% part time	Survey
Sweden	Brundin <i>et al.</i> (2017)	Working age	2015	12% full time, 42% part time	Survey

Employment rates also vary with the type of MS. In Norway, Lunde *et al.* (2014) found that individuals with RRMS have the highest employment rates, whereas those with SPMS have the lowest. This finding is supported by a Swedish study by Castelo-Branco *et al.* (2019), which confirmed that people with RRMS have lower levels of absenteeism compared to those with SPMS and PPMS.

Four studies provide information about the types of jobs or tasks that people with MS hold.

Machado *et al.* (2022) found that individuals with MS in Sweden experience more employment status transitions, especially just before and shortly after diagnosis.

Most of these transitions involve moving from employment to unemployment. Transitions to self-employment are relatively uncommon among people with MS. Even though more people with MS experienced unemployment, this did not significantly increase the risk of long-term sickness absence or disability pension.

A Norwegian report and a Danish research article both indicate that MS patients in non-physical jobs, such as office or sedentary work, have a lower risk of leaving the labour market (Skogli et al. 2023; Pflieger, Flachs & Koch-Henriksen 2010). Kjellberg & Ibsen (2020) find that almost half of people with MS in ordinary employment are employed in the public sector. Those with MS who work in a flex job are primarily employed in the public sector or in specific parts of the private sector. People with MS are less likely to be employed in small companies with fewer than 10 employees, and more than half of those with MS in a flex job are employed by larger companies with more than 250 employees.

Lunde *et al.* (2014) found that people with higher levels of education have higher employment rates. Since higher education is typically associated with better job opportunities, greater employability, higher wages and better job benefits, this may explain some of the differences in employment outcomes between those with and without higher education.

2.2 Disability pension and sickness absence

Many of the publications identified in this literature review examine disability pension and sickness absence as indicators of labour market attachment among people with MS, particularly with a focus on their progression over time. Studies conducted in Denmark, Finland and Sweden consistently find that the risk of disability pension or sickness absence increases as time progresses after disease onset. Both disability pension and sickness absence arrangements can be defined and structured in different ways in the individual Nordic countries. For example, there may be various options for working while receiving a disability pension. To better understand the arrangements in each country, we refer to the sections on employment initiatives and pension schemes, which are the first sections in each of the country chapters.

In Denmark, Pflieger, Flachs and Koch-Henriksen (2010) report that over time after disease onset people are less likely to avoid disability pension. 5 years after onset, 70% are still not receiving disability pension, but this number drops to 22% after 20 years. Wandall-Holm, Andersen *et al.* (2022) further confirm that the percentage of disability pensions rises significantly with age, increasing from 2% in the youngest working-age group (18-24 years) to 53% in the oldest (55-64 years). Kjellberg and Ibsen find that

the number of days receiving transfer income increases proportionally with the number of years since diagnosis (Kjellberg & Ibsen 2020).

Wandall-Holm, Andersen *et al.* (2022) find that the risk of disability pension is delayed if people with MS receive early treatment. 10 years after onset, the risk of receiving disability pension is 10% for people receiving treatment within 1 year. This increased to 15% for people receiving treatment 1-4 years after onset and 23% for people receiving treatment after 4-8 years. Pflieger, Flachs and Koch-Henriksen (2010; 2010) also examine the time from disease onset to disability pension. They find that the median time from MS onset to disability pension is 10 years (Pflieger, Flachs & Koch-Henriksen 2010). In another study, they observe that the average time from MS symptom onset to disability pension is 11.5 years (Pflieger, Flachs & Koch-Henriksen 2010). Kjellberg and Ibsen find that people with MS on average leave the regular labour market 5 years after diagnosis, whereas this number is 7 years for the control group. The average time from diagnosis to early retirement is 7 years in the examination period from 2007-2016³ (Kjellberg & Ibsen 2020). After 12 years, 50% of people with MS had left the labour market, with most of these individuals on disability pension. However, part of this population had been diagnosed with MS before the start of the examination period in 2007.

Two Finnish studies also investigate the average time from MS diagnosis to disability pension. Ruutiainen *et al.* (2016) report that the mean age for disability pension is 45 years, with an average time from diagnosis to retirement of 7 years and an average time from MS onset to disability pension of 14 years. Heinonen *et al.* (2020) find that retirement rates among people with MS have decreased following the widespread use of DMTs. They find that the median time from diagnosis to retirement was 8 years for those diagnosed before 1995 and 11 years for those diagnosed after 1995. A Swedish study by Landfeldt *et al.* (2016) found that the mean age of full-time retirement in their cohort was 43 years.

Some studies also point out that employment rates are already affected before the MS diagnosis. A Danish study by Jennum *et al.* (2012) identifies a decline in employment levels up to 8 years prior to diagnosis. Landfeldt *et al.* (2016) also find significant differences in sickness absence rates between people with MS and controls⁴, with

³ The time from diagnosis to leaving the regular labour market and receiving disability pension in (Kjellberg & Ibsen 2020) might be underestimated as the examination period was relatively short for measuring the time from diagnosis to disability pension, and a large portion of the population will therefore not have left the labour market by the end of the period, see section 3.3. The time from diagnosis to disability pension is longer than the time from diagnosis to leaving the regular labour market. This is because leaving the regular labour market might mean transitioning to other types of social benefits, while disability pension is often the final form of social benefit a person receives.

⁴ Controls or a control group is a comparable group of individuals who overall have the same characteristics as the experimental group. In the studies in this report, the experimental group of interest is people with MS, whereas the control group is a comparable group without MS. This helps the authors determine if a labour market outcome is specifically related to MS.

disparities emerging 15 years before MS diagnosis. In case of disability pension, a difference appears 3 years before the onset.

A Swedish study by Murley, Karampampa *et al.* (2020) reports that not everybody with MS goes from active employment to full-time sickness absence or disability pension over time. Some individuals experience increased sickness absence or disability pension around the time of diagnosis but later return to work, suggesting that temporary reductions in work capacity may be followed by a return to employment. The peak in sickness absence or disability pension occurs 1 year after diagnosis, with an average of 70 days. Consistent with Murley, Karampampa *et al.*'s findings, Castelo-Branco *et al.* (2019) observe that the annual mean number of sick leave days peaks around the time of diagnosis.

Additionally, studies find that older age at onset (Landfeldt *et al.* 2016), female gender, engagement in physical work, efferent onset symptoms (Pfleger, Flachs & Koch-Henriksen 2010) or delayed treatment for RRMS (Wandall-Holm, Buron *et al.* 2022) are all characteristics associated with a higher risk of disability pension.

2.3 Income and productivity losses

Several studies have explored the income and productivity losses associated with MS at both the individual and societal levels.

In Sweden, Landfeldt *et al.* (2018) identified a cumulative loss of disposable income during the first 10 years following an MS diagnosis. A significant reduction in income was observed after 5 years for women and after 9 years for men. However, they found no significant difference in income between MS patients and controls before the onset of the disease. However, in Denmark, Pfleger, Flachs and Koch-Henriksen (2010) reported that, at the time of MS onset, patients had slightly lower incomes than controls. Over time, the control group experienced a steady increase in income, whereas people with MS had stable incomes for about 10 years after onset before experiencing a decline.

Four studies – two from Finland and two from Norway – examined productivity losses at the societal level due to MS. Ruutiainen *et al.* (2016) found that early retirement was the biggest factor in Finland's total economic burden, accounting for 37% of the total costs on society level. Overall, productivity losses represented 44% of the total costs. Another Finnish study by Purmonen *et al.* (2020) found that different types of MS lead to varying costs. SPMS had the highest yearly cost, followed by RRMS. PPMS, in contrast, had much lower annual costs compared to the other types. In a Norwegian study, Svendsen *et al.* (2012) found that 61% of the total economic costs related

to MS patients were due to reduced work participation. Most of these reduced work costs were attributed to early retirement and reduced working hours. In another Norwegian study, Skogli *et al.* (2023) find that productivity loss from reduced working capacity, presenteeism and tax costs constitutes 46% of the total social economic costs.

Only one study, conducted by Ruutinen *et al.* (2016) in Finland, investigated the costs related to informal care associated with MS. This study found that informal care accounted for 13% of the total costs, making it the third-largest contributor to productivity losses in their assessment.

2.4 Working life and symptoms affecting working life

Two Danish studies, both based on qualitative data, explore how MS affects the everyday working life of those diagnosed with the disease.

Martin and Mehlsen (2020) found that uncertainty about the progression of MS and its impact on work and labour market participation is a significant concern among people with MS. Other challenges include feelings of vulnerability to job cuts, the need to give up career aspirations and a sense of identity loss. As the disease progresses, adjustments to working hours and job tasks often become necessary. Employers identified flexibility, accommodation and open communication as crucial factors in managing employees with MS. However, the stigma surrounding the disease can sometimes lead to employees and employers avoiding discussions about the disease and the future of the employee with MS.

Martin and Frøslev-Thomsen (2022) investigated the advantages and disadvantages of working from home for people with MS. They found that the most widely recognised benefits include flexibility, the ability to adapt work schedules to align with energy levels and reduced absenteeism. On the other hand, the primary disadvantages include the lack of social interaction and collaboration with co-workers as well as diminished coordination at the workplace.

Several studies have investigated how different types of MS and specific symptoms affect working life.

A Danish study by Chalmer *et al.* (2019) found that individuals with clinically stable MS are more likely to maintain employment, particularly in the first 5 years after starting treatment. Additionally, four studies – three from Denmark (Kjellberg & Ibsen 2020; Chalmer *et al.* 2019; Rasmussen *et al.* 2017) and one from Sweden (Brundin *et al.* 2017) – confirmed that an increased EDSS score negatively affects employment. The

EDSS is used to measure the level of disability among people with MS. However, Rasmussen *et al.* (2017) noted that some symptoms, such as fatigue, are not included in the EDSS score, potentially leading to an underestimation of the impact of milder MS symptoms.

Two studies from Denmark and one from Finland have explored the specific symptoms of MS that affect working life. All three studies found that fatigue and cognitive difficulties are among the symptoms that had the largest impact on working life, with fatigue being the most disruptive (Rasmussen *et al.* 2017; Scleroseforeningen 2022; Vaha 2017). Both of these symptoms are considered 'invisible' (Vaha 2017). The two Danish studies also identified mobility problems as a significant challenge in the workplace (Rasmussen *et al.* 2017; Scleroseforeningen 2022). Vaha (2017) further highlighted that as modern work becomes increasingly cognitively demanding, even mild symptoms can pose significant challenges for individuals with MS in their professional lives.

2.5 Knowledge gaps regarding MS and labour market participation in the Nordic countries

As described above, the identified literature provides information on labour market attachment, employment rates, disability pension and sickness absence and income and productivity loss among people with MS. Some studies examine correlations between various factors, such as symptoms, job types, or MS subtypes, and labour market attachment. Additionally, a few studies explore how symptoms impact working life or describe the everyday challenges faced by people with MS in the workplace.

However, the literature on MS and labour market participation in the Nordic countries remains relatively limited. Based on this literature review, we have identified the following knowledge gaps:

- Much of the identified literature focuses on sickness absence or disability pension. Very few studies address people with MS who are still employed. There is limited information about e.g. job types, work assignments, requirements for individuals with MS, career changes or reasons behind job choices.
- While a few studies report flex job employment rates, no studies have been identified that explore the development of working conditions, alternative employment arrangements or schemes aimed at retaining people with MS in the workforce or improving their working conditions.

- One of the initial aims of this literature search was to identify studies evaluating the effectiveness of initiatives designed to maintain work participation or facilitate dignified retirement for individuals with MS. However, no such studies were found.
- Two qualitative studies mention how employers perceive having employees with MS. However, no studies investigate in depth how employers perceive having an employee with MS, and how this potentially generates job barriers and opportunities for people with MS.
- The number of studies on MS and labour market participation varies across the Nordic countries, with several studies from Denmark and none from Iceland. A total of 26 studies were identified, but all of these focus on MS within a single country. Despite the fact that the Nordic countries have some of the highest prevalence rates of MS globally, no studies have investigated or compared MS across the Nordic countries and no studies have focused on Iceland.
- The medical conditions and the ability to diagnose people with MS earlier have improved in recent years. This also improves the chances of retaining labour market attachment. New research on new data is therefore much needed to better understand the development for labour market outcomes in the Nordic countries.

3 Denmark

This chapter presents a review of the literature on MS and labour market attachment in Denmark, drawing from a total of 12 publications. The chapter begins with a brief overview of MS in Denmark, followed by an examination of relevant employment initiatives and pension schemes available in the country.

Table 3.1 provides an overview of the studies included in this chapter. It indicates which themes each study addresses. Large and bold **X**'s highlight the primary theme that each study contributes to, which also determines the theme under which the study is presented. Small x's indicate additional themes that the publication further helps to clarify.

In Denmark most studies focus on disability pension and sickness absence and working life. Many studies have labour market attachment as a secondary theme too.

Table 3.1 Included studies from Denmark by the focus of the study

Study	Labour market attachment	Disability pension and sickness absence	Income and productivity loss	Working life
Jennum <i>et al.</i> (2012)	X	x		
Rasmussen <i>et al.</i> (2017)	x			X
Wandall-Holm <i>et al.</i> (2022)		X	x	
Kjellberg and Ibsen (2020)	x	X		
Pfleger, Flachs and Koch-Henriksen (2010)		X		
Wandall-Holm <i>et al.</i> (2023)	x		X	
Wandall-Holm <i>et al.</i> (2022)		X		
Chalmer <i>et al.</i> (2019)		X	x	
Pfleger, Flachs and Koch-Henriksen (2010)			X	
Scleroseforeningen (2022)	x			X
Martin and Mehlsen (2020)				X
Martin and Frøslev-Thomsen (2022)				X

Note: Large and bold **X**'s highlight the primary theme that each study contributes to, which also determines the theme under which the study is presented. Small x's indicate additional themes that the publication further helps to clarify.

3.1 Employment initiatives and pension schemes in Denmark

In Denmark, a variety of employment initiatives and pensions schemes are available for people with MS or other disabilities affecting the labour market attachment.

Flex job

Flex Job (fleksjob) is a flexible employment arrangement designed to accommodate the needs of individuals with lasting and reduced working capacity. Flex job arrangements may include part-time work, telecommuting options, job sharing and modified work schedules tailored to the individual's abilities and limitations. The aim of flex jobs is to promote greater inclusion and participation in the workforce by removing barriers to employment for individuals with disabilities.

Rehabilitation programmes

Rehabilitation programmes are options offered to individuals with reduced working capacity due to physical, psychic or social reasons. Rehabilitation usually takes the form of education, training or retraining, but other alternatives may also be available. The aim of rehabilitation is to help individuals with reduced working capacity to either return to work or find alternative employment options that suit their abilities and health. Rehabilitation involves an assessment of the person's capacity and needs, and different support options from specialists like occupational therapists and job counsellors. Ultimately, rehabilitation aims to promote workforce participation despite the challenges posed by the condition, fostering financial independence and social inclusion. In Denmark, the rehabilitation takes place in the municipalities.

Sickness allowance

Individuals who are unable to work due to an illness may be eligible for a sickness allowance. The sickness allowance provides financial support to compensate for lost income during periods of illness or incapacity for work. Employees, self-employed individuals and unemployed individuals may all be eligible for sickness allowances. The allowance is typically administered by the municipality or employer and is intended to ensure financial stability for individuals while they focus on their health and recovery. However, sickness allowance is only available for a limited time period.

Paragraph 56 and Paragraph 58a

In Denmark, Paragraph 56 and Paragraph 58a of the Danish Sickness Benefits Act are designed to support individuals with chronic or long-term illnesses. These rules allow individuals who are unable to work due to their illness to receive sickness benefits. Paragraph 56 is targeted at employees, whereas paragraph 58a supports self-employed individuals. These rules recognise that certain chronic conditions, such as

MS, can make it difficult to keep a job over a long period of time. Therefore, the paragraphs ensure financial support for individuals with MS who need extended sick leave. The aim of these paragraphs is to help employees stay in their current jobs and to ensure that self-employed individuals can continue to manage their businesses.

Transportation allowance

Additionally, people with MS can receive a transportation allowance (befordringsfradrag), which is a tax deduction for travelling expenses available to individuals in the labour market who incur higher transportation costs due to chronic illness or disabilities.

Disability pension

Disability pension is a scheme available for individuals who are no longer able to work due to, for example, the progression of the MS. This scheme allows them to retire early and receive pension benefits. Disability pension provisions in Denmark allow individuals to access their pension benefits before reaching the standard retirement age. The disability pension is available only for individuals with a permanent reduction in work capacity. Eligibility is typically determined through a comprehensive assessment by Danish authorities, considering factors such as the severity of the disability and its impact on the individual's ability to work. Disability pension is typically provided as a lifelong pension, offering continuous financial support until the individual reaches the standard retirement age. This ensures that people with permanent reduced work capacity – in some cases people with MS – have a reliable source of income to cover living expenses and medical needs until they reach the standard retirement age.

3.2 Labour market attachment

Jennum *et al.* (2012) conducted a study using national registers to examine the societal costs associated with MS, focusing on all patients diagnosed over an 8-year period in Denmark. The study found that a higher proportion of individuals with MS relied on social services compared to controls, while fewer received income from employment. Specifically, 39% of people with MS had income from employment compared to 67% among the control group. Furthermore, 87% of those with MS received public transfers as a source of income, with 12% receiving a pension, 15% on sick pay and 64% on other forms of public assistance. In contrast, only 25% of the control group relied on public transfers.

The study also highlighted that the employment rate among people with MS decreased significantly after diagnosis. Moreover, employment levels were already impacted up to 8 years prior to diagnosis, with a further decline after the diagnosis was

confirmed. This suggests that many patients may experience substantial reductions in their working capacity even before they are formally diagnosed with MS.

3.3 Disability pension and sickness absence

Wandall-Holm, Andersen *et al.* (2022) investigate how socioeconomic factors such as income and disability pension are affected by age for people with MS using data from nationwide registers. The study found that in 2018, 38% of MS patients and 19% of controls had no income from employment. Among the 18-24 age group, 30% of MS patients had no income from work (compared to 18% among controls), a figure that increased to 54% among the 55-64 age group (compared to 24% among controls).

Wandall-Holm, Andersen *et al.* (2022) also find that the percentage of MS patients on disability pensions rose sharply from 2% in the youngest age group to 53% in the oldest, while the corresponding figures for the control group increased from 1% to 14%. Overall, 31% of MS patients were on disability pensions compared to 8% of the control group. These data indicate that the working-age population of people with MS in Denmark has a 23 percentage points higher prevalence of receiving disability pensions compared to controls.

Another study by Wandall-Holm, Buron *et al.* (2022) examined the association between the time from RRMS diagnosis to treatment and the risk of disability pension in a population-based cohort study. The study found that early treatment of RRMS, compared to later treatment, was associated with a reduced risk of receiving a disability pension. Patients who initiated treatment later than 1 year after onset had a higher risk of receiving a disability pension compared to those who began treatment within the first year. This risk increased with further delays in treatment initiation. Specifically, patients who started treatment between 1-4 years after onset and those who began treatment between 4-8 years after onset exhibited higher risks of receiving a disability pension. 10 years after onset, the risk of receiving a disability pension was lowest among patients who began treatment within 1 year (10%), higher in those with a 1-4-year delay (15%) and highest among those with a 4-8-year delay (23%). The risk of receiving a disability pension was 37% higher in the intermediate group and 94% higher in the late group compared to the early group.

A report from 2020 (Kjellberg & Ibsen 2020) examined the labour market participation of people with MS in Denmark using data from national registers covering the period from 2007 to 2016. The study found that both the EDSS score and the number of days receiving transfer income increase proportionally with the number of years since diagnosis. At the time of diagnosis, 5% of people with MS were on a disability pension; this figure rose to 72% after 25 years. After 12 years, 50% of people with MS had left

the labour market, with most of these individuals on disability pension. However, part of this population had been diagnosed with MS before the start of the examination period in 2007.

Labour market participation and ordinary employment decreased over time among people with MS according to (Kjellberg & Ibsen 2020). Nearly half of the people with MS (44%) left the regular labour market during the study period (2007-2016) compared to only 6% of the control group. People with MS who left the regular labour market in the examination period had been diagnosed for 5 years on average before leaving the regular labour market, while it was 7 years for the control group.

Among those who left ordinary employment, only 4% transitioned to an age-related pension. Individuals with MS who left the regular labour market on an age-related pension typically had an EDSS score between 2.5 and 2.8. A one-point increase in the EDSS score rose the risk of leaving ordinary employment for a flex job or for receiving flex/unemployment benefits by 170%. The risk of transitioning from ordinary employment to a flex job were 34 times higher for people with MS than for the control group. Similarly, the risk of moving from ordinary employment to disability pension were 13 times higher for people with MS.

Furthermore, Kjellberg and Ibsen (2020) found that 17% of the individuals with MS had transitioned to disability pensions during the examination period (3% for the control group). This group had an average EDSS score of 3.8. The average age for people with MS was 43 years when they first received disability pension, while the average age was 47 years for the control group. The authors report that the average time from diagnosis to early pension retirement for this group was 7 years. However, the examination period (2007-2016) was relatively short for measuring the time from diagnosis to disability pension, and a large portion of the population will therefore not have left the labour market by the end of the period. The group that had transitioned to disability pension during this period is therefore not necessarily representative of all people with MS, and the calculated time from diagnose to disability might therefore be underestimated.

Almost 1 in 5 people with MS in ordinary employment have experienced a period of sickness absence, whereas this number was 1 in 10 for the control group. For each 0.5-point increase in the EDSS score, the risk of taking another period of sickness absence increased by 20%. Among people with MS who have had a sickness absence lasting at least 4 weeks, 69% returned to ordinary employment (67% returned to the same workplace and 2% returned to work at a different company). In comparison, 75% of the control group returned to ordinary employment.

Kjellberg and Ibsen (2020) also showed that the type of workplace and industry played a significant role in retaining people with MS. Nearly half of the people with

MS in ordinary employment worked in the public sector. In the private sector, most people with MS were employed in finance/insurance companies or the manufacturing industry. People with MS were less likely to be employed in small companies with fewer than 10 employees. Those with MS who worked in a flex job were primarily employed in the public sector or in the private sector within communication/information, finance/insurance or real estate. More than half of those with MS in a flex job were employed by larger companies with more than 250 employees. The authors conclude that the public sector was better at retaining people with MS in ordinary employment, while the private sector was more successful at retaining people with MS in flex jobs.

A study by Pflieger, Flachs and Koch-Henriksen (2010) examined the time to cessation of work or the awarding of a disability pension considering various demographic and clinical factors. This historical, prospective cohort study, based on national registry data, revealed that, on average, MS patients received a disability pension 11.5 years after symptom onset. However, the type of symptoms at onset significantly influenced this timeline. Patients with afferent or brainstem symptoms had a longer average time to disability pension, at 13 years, whereas those with efferent symptoms had a shorter average time of 8.7 years.

The risk of exiting the labour market varied significantly among different groups. Patients in non-physical jobs had a 70% lower risk of leaving the labour market compared to those in physical jobs. Gender also played a critical role, with male patients having a 27% lower risk of being awarded a disability pension compared to female patients.

The study identified a high-risk profile for early exit from the labour market, characterised by women engaged in physical work, with efferent onset symptoms and who were aged 30 or older at onset. The researchers thereby concluded that age at onset, gender, type of work and onset symptoms are significant predictors of the risk of being awarded a disability pension among MS patients.

Chalmer *et al.* (2019) investigated the risk of disability pension and income loss among patients with clinically stable disease, using data from national registers. Patients with MS were categorised into two groups: those with clinically active disease, characterised by relapse activity or a 6-month worsening of EDSS scores, and those with clinically stable disease. The study found that patients with clinically stable disease after 3 years of treatment were more likely to maintain employment. Being in the clinically stable group was associated with a reduced risk of receiving a disability pension, especially within the first 5 years after treatment initiation. In this period, the clinically stable group had a 57% lower rate of receiving a disability pension.

The study also observed a reduction in income loss for both clinically active and clinically stable patients, although this effect was less pronounced in the stable group.

Among those with clinically active disease, the risk of adverse outcomes was primarily linked to worsening EDSS scores. The study found that for each one-point increase in EDSS over 3 years, the hazard rate of income loss increased by 28% and the hazard rate of receiving a disability pension increased by 57%. Socioeconomic status was also identified as a significant prognostic factor for both disability pensions and income loss, suggesting that even in a country with high equality like Denmark, socioeconomic status at the start of treatment influences the risk of disability pension.

3.4 Income and productivity losses

Pfleger, Flachs and Koch-Henriksen (2010) explored the trajectories of working life and career progression for individuals with MS, focusing on disability pension, temporary unemployment and income trends using data from nationwide Danish registers. Their study showed notable differences in income between people with MS and controls. Initially, at the time of MS onset, patients had an income slightly lower than controls. However, while the control group experienced a steady increase in income over the years, the income of MS patients remained stable for about 10 years before it began to decline. 20 years after onset, the mean gross income of the MS patients was approximately 70% of that of the controls.

Pfleger, Flachs and Koch-Henriksen (2010) also found that, at the onset of MS, 0.8% of patients received disability pensions compared to 0.7% of controls. Furthermore, for individuals who did not receive disability pension, the likelihood of remaining without disability pension decreased significantly over time for people with MS. 5 years after onset, the probability of remaining without disability pension was 70% for MS patients (compared to 97% for controls), dropping to 45% after 10 years (93% for controls), 31% after 15 years (89% for controls) and 22% after 20 years (86% for controls). The median time from MS onset to disability pension was 10 years for patients, compared to 24 years for controls.

Lastly, the study observed that the frequency of temporary unemployment at 5, 10 and 15 years after entering the labour market was approximately the same for both MS patients and controls.

A study by Wandall-Holm *et al.* (2023) examined the socioeconomic aspects of MS among elderly patients using data from national registers, covering all living MS patients aged 50 years or older as of January 1, 2021. This study highlighted a significantly weaker connection to the labour market for individuals with MS compared to controls. Among those under 65 years old, only 46% of people with MS received income from employment, compared to 79% of the control group. For those aged 65 and older, the gap persisted but was less pronounced, with 6% of MS patients

receiving employment income compared to 16% of controls. The primary source of income also differed markedly between the groups. Among those under 65, only 40% of people with MS had 'labour' as their main income source, while 48% relied on 'pensions'. In contrast, 77% of the controls had labour as their main income source, with only 13% relying on pensions.

Moreover, among those under 65 who were employed, MS patients earned a median yearly income of €48,500, significantly lower than the €53,500 earned by controls. People with MS were also more likely to work part-time (46% compared to 19% of controls) and to have over 30 sick days per year (13% vs. 9%). However, the study found that if an individual with MS maintained income from employment, they generally followed a similar income trajectory as the controls. These findings illustrate that people with MS not only have a lower employment rate but also experience lower earnings and more frequent work absences compared to their non-MS counterparts.

3.5 Working life and symptoms affecting working life

Rasmussen *et al.* (2017) conducted a study investigating the costs, health care expenditures, work capacity, health-related quality of life and symptoms among patients with MS. Data were collected through a retrospective questionnaire. The study found that 73% of employed individuals with MS reported that the disease had impacted their working ability, while 15% indicated they had no work-related issues due to MS. The most disruptive symptoms in the workplace were fatigue (69%), cognitive difficulties (33%), mobility issues (30%), pain (21%) and low mood (7%).

In the same study the authors report that of those within the working age, 43% were either formally employed or self-employed, with 85% of this group working part-time. However, only 17% of those working part-time did so due to MS. Employment significantly decreased with disease progression, and among non-employed patients below retirement age, 52% attributed their exit from the workforce to MS. Furthermore, the study revealed that workforce participation dropped below 50% once a patient's EDSS score reached 3. Since physical disability is not widespread among those with an EDSS score around 3, this suggests that symptoms not included in the EDSS score, such as fatigue, play a significant role in labour market participation.

A study by the Danish MS Society (Scleroseforeningen 2022) explored everyday life and living conditions among people with MS, drawing on survey data. This study found that fatigue, sensory disturbances and difficulty walking were the most prevalent symptoms among the patients. Cognitive disturbances were reported by 56% of

participants, with memory problems (87%) and concentration difficulties (84%) being the most common. Fatigue was identified as the most intrusive symptom affecting working life, cited by 34% of respondents, followed by cognitive disturbances (24%) and physical limitations or difficulty walking (16%).

The study also found that 17% of participants were working full-time under normal conditions, and 37% had, at some point, changed jobs or job functions due to MS. Among those currently employed or studying, 38% were engaged full-time, while 30% worked or studied less than 15 hours per week. Of those not working full-time, 90% attributed this to MS, with 4% citing MS as a partial reason. Additionally, 28% received a disability pension, while 24% were in a flex job.

VIVE has, in two recent reports (Martin & Frøslev-Thomsen 2022; Martin & Mehlsen 2020), investigated the experiences of working life for individuals with MS. Both of these reports are based on qualitative data.

In the first report from 2020 (Martin & Mehlsen 2020), VIVE explores how people with MS perceive the impact of the disease on their working life and how employers experience having employees with MS. The report is based on interviews with 10 employees with MS and 10 employers who have employees with MS.

The employees with MS said that they had to rearrange both their work and private lives after receiving an MS diagnosis (Martin & Mehlsen 2020). As MS often progresses differently from patient to patient, many of the interviewees expressed significant uncertainty about how their disease would develop and how much it would impact their working life and labour market participation. This uncertainty sometimes led employees to withhold information about their condition from co-workers or employers. However, this decision often depended on the progression of the disease, their personal identity, their role as an employee and their relationships with their employer and co-workers. Some employees also expressed that they felt a disconnect between the expectations of a 'good employee', characterised by proactivity and energy, and their actual symptoms, leading to feelings of being overwhelmed by high demands and a need to manage their professional image carefully.

Other employees mentioned feeling vulnerable in relation to job cuts, feeling a strong need to hold onto their jobs and having to give up on their career aspirations. Many experienced this as a loss of identity. However, when the disease progresses, many employees report that their priorities shift, with a greater focus on family life and less on their careers (Martin & Mehlsen 2020).

Some employees in the study reported that their work tasks and conditions needed to be continuously adjusted as the disease progressed. In particular, working hours

often had to be modified. Others mentioned different types of support, such as specialised equipment, that were necessary to accommodate their needs.

In general, the employees with MS highlighted the importance of a positive relationship with their employer, the perception that their employer considers their needs and the employer's knowledge of the disease and available support resources as critical factors for maintaining a good working life.

Additionally, employers identified flexibility, accommodation and open communication as important factors when managing an employee with MS. However, they also noted that the focus on the needs of the employee with MS should not come at the expense of other employees. Employers also recognised the importance of understanding MS and its progression. They emphasized the value of honesty and dialogue but acknowledged that transparency about symptoms could affect their willingness to invest in the employee's further training or development. Discussing cognitive symptoms or the future at the workplace was described as challenging due to uncertainty about the future and the perceived taboo surrounding memory and concentration problems. The study reports that this often resulted in employees and employers avoiding discussions about the future or the cognitive symptoms of MS that could affect the employee's ability to work (Martin & Mehlsen 2020).

A more recent study (Martin & Frøslev-Thomsen 2022) investigated the advantages and disadvantages of working from home for people with MS. Although this study was conducted in the context of the COVID-19 pandemic, it provides insights into the general experiences of working from home. The data are based on interviews with 16 employees with MS and 10 employers. The study found that working from home was generally associated with positive outcomes for both employers and employees and the study indicates that working from home could be an effective strategy for keeping people with MS in the labour market.

The greatest advantages of working from home, as described by the employees in the study, included increased flexibility, allowing them to adapt their work schedules to their energy levels rather than conforming to the traditional rhythm of the workplace. They could work when they had the most energy and take breaks as needed, leading to increased productivity, higher quality performance and more energy for their personal lives. Additionally, employees felt that the increase in online meetings and virtual interactions with co-workers made their MS-related limitations less noticeable, allowing their professional identity to take precedence.

Employers noted that working from home also led to reduced absenteeism due to illness and offered better opportunities to accommodate the individual needs of employees with MS.

However, some disadvantages of working from home were also noted. The absence of social interaction and professional collaboration with co-workers, as well as diminished internal coordination, were seen as challenges. Additionally, employees expressed concerns about the use of 'hot desks' or shared workspaces when working from home, as it meant losing their own office space, which could cause additional stress (Martin & Frøslev-Thomsen 2022).

4 Finland

This chapter discusses MS and labour market participation in Finland, based on four Finnish publications.

Initially, we present data on the prevalence of MS in Finland, followed by a description of relevant employment initiatives and pension schemes.

In Table 4.1, we provide an overview of the included studies from Finland and how they are distributed on the identified themes. In Finland, two studies mainly focus on disability pension and one focuses on sickness absence and one focuses on working life. However, three of the studies also have labour market attachment as a secondary theme.

Table 4.1 Included studies from Finland by the focus of the study

Study	Labour market attachment	Disability pension and sickness absence	Income and productivity losses	Working life
Ruutiainen <i>et al.</i> (2015)	x		X	
Purmonen <i>et al.</i> (2019)	x		X	
Heinonen <i>et al.</i> (2020)		X		
Vaha (2017)	x			X

Note: Large and bold **X**'s highlight the primary theme that each study contributes to, which also determines the theme under which the study is presented. Small x's indicate additional themes that the publication further helps to clarify.

4.1 Employment initiatives and pension schemes in Finland

In Finland, several employment initiatives and pension schemes are available for people with MS. Increasing labour market participation for individuals with different disabilities is a key area of interest for both ministries and organisations in Finland.

Occupational health services

For individuals in the labour market, occupational health services are available. In Finland, every employee has access to statutory occupational preventive health services arranged by the employer. The coverage of these services varies, but support for work ability and return to work is mandatory. Occupational health services must be

adjusted to the work ability of employees who are at an increasing risk of incapacity to work (Ministry of Social Affairs and Health 2022). Employers are required to make 'reasonable adjustments' in accordance to the Non-Discrimination Act, although the flexibility of the employer may vary. If accommodations or additional support for the employee are needed, occupational health services can facilitate negotiations with the employer (Ministry of Justice 2014).

Sickness absence and sickness allowance

In case of longer periods of sickness or inability to work, different forms of sickness absence and sickness allowances are available. When an employee falls ill, they are entitled to their normal salary for the first 1+9 days. However, there are multiple collective agreements in Finland that extend the fully paid sick leave, usually for 60 days, and provide for partially paid sick leave, typically at two-thirds of the salary, for up to 120 days. In case of longer periods of reduced work capacity, the employee is entitled to a sickness allowance from the Social Insurance Institution of Finland, Kela. The allowance is based on the individual's earnings over the last 12 months and is approximately 70% of those earnings, or at least €31.99 per day, paid 6 days per week. The sickness allowance is paid for a maximum of 300 days over a period of 2 years. Partial sickness allowance is paid for a maximum of 150 days within a 2-year period.

Vocational rehabilitation

Vocational rehabilitation is an option for people with reduced working capacity or a risk of reduced working capacity in the future. The objective is to help them return to or stay in the workforce by improving their ability to work, if they can no longer perform their previous job due to health reasons or if it is likely that working ability will decrease in the following 5 years.

In Finland, vocational rehabilitation can be granted by either the pension insurance companies or Kela. Individuals with pension insurance can apply for and be granted vocational rehabilitation by insurance companies, if they are in employment and have a risk of reduced working ability due to health reasons. Usually, vocational rehabilitation includes options such as counselling and guidance, work trials, job training or education/re-education. The individual will be paid a rehabilitation allowance if they are unable to have gainful employment during the vocational rehabilitation. The allowance is equivalent to a disability pension, with a rehabilitation increment of 33%. If the individual is outside the labour market, the Social Insurance Institution of Finland, Kela, pays the rehabilitation allowance based on the same foundation as the sickness allowance. This is targeted people with a diminished working ability that makes it difficult to find employment. This is typically relevant for younger people outside the labour market.

The Public Employment and Business Services

If an unemployed person has been searching for a job for 6 months or more, the Public Employment and Business Services (Ministry of Economic Affairs and Employment – a state authority that organises and provides employment and economic development services) or the local government can help arrange job search discussions. This might include career guidance, job search training and work try-outs. The objective of these options is to improve the chances of getting or keeping a job for a person affected by a disability or illness. The Public Employment and Business Services or local government pilot can also grant a pay subsidy to employers if they have an employee with a disability or illness that affects their working ability. Additionally, employers can be granted economic support (up to €4,000) by The Public Employment and Business Services if they need to improve working conditions to accommodate an employee with a disability.⁵

Disability pensions

If an individual has a continued full-time sickness or incapacity to work after the maximum period of sickness allowance, they can receive a disability pension. The disability pension can be temporary (referred to as a cash rehabilitation benefit) or permanent, depending on how long the incapacity for work is estimated to continue.

Earning-related pensions accrue for individuals with pension insurance. For those with pension insurance, the disability pension is granted by one of the four private pension insurance companies (Ilmarinen, Varma, Elo, Veritas) or the public pension insurance company (Keva) which is responsible for the pensions of people working in municipalities, church or the state. The amount of the pension is based on a person's earnings during their entire career. However, the pension of people retired early due to disabilities will remain low, and in these cases the accumulated pension is supplemented by a 'future pension' that is based on the person's earnings in the last 5 years. The national pension and the guarantee pension ensure a minimum income for individuals with little or no earning-related pensions. These pensions can be granted wholly or partially by the Finnish Social Insurance Institution, Kela.

Additionally, it is possible to continue working even if you have been granted a disability pension in Finland. However, there are earning limits to consider. For a full-time disability pension, you can earn up to 40% of your average earnings from the last 5 years. For a part-time disability pension, you can earn up to 60% of your average earnings from the last 5 years. Furthermore, it is possible to have a *dormant pension*, which allows a person with a disability pension to return to work for a

⁵ A new reform, starting in 2025, will transfer the services of The Public Employment and Business Services to the municipalities in Finland.

shorter period, ranging from 3 months to 2 years. When the pension is dormant, there is no limit on how much you can earn.

Initiatives by the Finnish Neuro Society

In addition to these employment initiatives and pension schemes, the Finnish Neuro Society has been involved in various projects concerning people with MS. These initiatives aim to produce and disseminate information about labour market participation and different disabilities. The focus areas include entrepreneurship, job application methods, managing cognitive symptoms in the workplace and job application strategies for young people with disabilities, among other topics. Furthermore, the Finnish health and employment authorities also initiate other smaller programmes aimed at strengthening employment efforts for people with long-term illnesses, including MS, but these are not described further here.

4.2 Disability pension and sickness absence

Heinonen *et al.* (2020) conducted a retrospective survey of patients with MS treated at the Department of Neurology, Kanta-Häme Central Hospital, in Finland between 1978 and 2015. The aim of the study was to examine retirement rates over the decades, particularly after the introduction and availability of DMTs. The year 1995 was chosen as a division point, as DMTs have been increasingly available since then. DMT's could for example be pills or injections (MS Society 2022).

The study finds that disability pension among people with MS has decreased in the last 2 decades. Before 1995, the median time from diagnosis to retirement was 8 years, which increased to 11 years for people diagnosed after 1995. There was no statistically significant difference in retirement rates between those with RRMS or SPMS after 1995. The study also indicates that not using DMTs at any point during the disease was a risk factor for early disability pension among people with RRMS (Heinonen *et al.* 2020).

4.3 Income and productivity losses

Ruutiainen *et al.* (2016) investigate the economic costs and health-related quality of life burden of MS. The study is based on data from a questionnaire completed by 553 people with MS in Finland. The total mean annual cost per person with MS is estimated at €46,994. Productivity losses due to early retirement were the most significant contributor to the total cost burden, accounting for 37% of the total costs. Overall productivity losses were estimated to be 44% of the total costs. These losses

increased steadily with disease progression and were highest among patients with an EDSS score of 5. The overall employment rate among people with MS was 35%.

Among the participants, 56% retired early due to MS, with the mean age for disability pension being 45 years. The average time from MS diagnosis time to disability pension was 6.7 years, while the average time from MS onset to disability pension was 13.5 years. Additionally, 38% of employed people with MS had to change their job type or working hours, leading to reduced income (Ruutiainen et al. 2016).

The study also found that informal care significantly impacted the total costs associated with MS. Informal care accounted for 13% of the total costs, making it the third-largest contributor to productivity losses. The mean time of informal care provided by family or friends was 10.5 hours per week, corresponding to an annual cost of €6,035 per patient. While informal care is not directly relevant to the labour market attachment of people with MS, it is relevant to the overall labour market costs due to MS (Ruutiainen et al. 2016).

Purmonen *et al.* (2020) also investigate the costs of MS on a society level. They use survey data and 498 patients with MS were included in the finale sample. The authors find that the annual economic costs varied across different types of MS. SPMS had the highest annual cost of €71,177. For PPMS the annual cost was €51,082 and for RRMS it was €36,492. Early retirement accounted for 39% for RRMS patients and 43% for SPMS patients. For PPMS patients, early retirement and direct health care accounted for 28% each.

The employment rate for MS patients were 34%. Of these, 67% were working full time. However, the employment rate also varied across types of MS. The employment rate was 11% for PPMS (of which 40% were working full time). For SPMS and RRMS the employment rates were 19 and 52% respectively (of which 50 and 72% were working full time) (Purmonen et al. 2020).

4.4 Working life and symptoms affecting working life

A study by Vaha (2017) examined the working life of people with MS within the working age range of 18-64 years. Data were collected through an online questionnaire sent to working-aged members of the Finnish Neuro Society. Of the respondents, 59% were actively participating in the workforce.

The study finds that 46% of people with MS were employed. 38% were working full time, while 8% were working part time.

The subjective perception of working ability among the working-age population with MS was relatively good. However, MS caused a variety of symptoms that impacted working life, with the majority being perceived as mild. As working life in general becomes more cognitively challenging, even mild symptoms can pose significant challenges. Additionally, invisible symptoms were perceived as more common challenges due to the development of better treatments positively affecting the physical condition of people with MS (Vaha 2017).

According to Vaha (2017), respondents were asked about both what they experience as mild symptoms and severe symptoms. The most common severe symptom found in the study was fatigue (20%). The most common mild symptoms were fatigue (64%) and problems with concentration (62%). Whether the symptoms were considered severe or mild, fatigue is therefore the most common symptom.

Employed individuals with MS perceived remission regarding their disease and support from co-workers and employers as the two most important factors affecting their working life. The study found that approximately 80% of respondents had been open about their disease and challenges at work. Additionally, the division of domestic chores influenced the ability of employed individuals to work effectively (Vaha 2017).

5 Iceland

The purpose of this chapter has been to present information about MS and labour market in Iceland. However, it has not been possible to identify research literature specifically concerning MS and labour market participation in Iceland. This gap is confirmed by an Icelandic literature review from 2018 (Maltseva 2018), which also found no relevant data and concludes that more research on MS and labour market dynamics in Iceland is needed.

Therefore, this chapter will focus on presenting the employment initiatives and pension schemes available in Iceland for individuals with MS.

5.1 Employment initiatives and pension schemes in Iceland

In Iceland, a range of employment initiatives and pensions schemes are available for individuals with MS and other disabilities that affect their ability to participate in the labour market.

Vocational rehabilitation

Vocational rehabilitation is an option aimed at enhancing the working capacity of individuals with health issues who seek increased participation in the labour market. The main vocational rehabilitation fund and NGO in Iceland is VIRK (VIRK 2024). VIRK offers targeted services, collaborating with trade unions, professionals, companies and institutions to create diverse opportunities for individuals with reduced work capacity. VIRK also engages in prevention, development projects and education to prevent individuals from exiting the labour market.

Pension funds

In Iceland, there is a mandatory co-insurance system that requires employees and employers to contribute to pension funds. Employees and self-employed individuals aged 16 to 70 must contribute 4% of their total salary to a pension fund, while employers contribute a minimum of 11.5% of the employee's total salary. The purpose of these pension funds is to ensure that members receive a retirement pension and to provide protection for them and their families against loss of income due to disability among other things. Multiple pension forms can be of relevance for individuals with MS:

Rehabilitation pension

Rehabilitation pension is intended to support individuals who cannot participate in the labour market due to an accident or illness. The objective is to help them regain their ability to work or enhance their employability. Rehabilitation pensions provide income support during the rehabilitation process. They are available to individuals between the age of 18 and 67 who have lived in Iceland continuously for at least 12 months and are actively participating in vocational rehabilitation under professional supervision.

Disability pension

Disability pension is for individuals with a 75% disability who are permanently unable to work. Disability pensions provide financial support while their disability assessment is valid. Disability pension is aimed at individuals between the ages of 18 and 67 who have lived in Iceland for at least 3 years. Additionally, it is a requirement that rehabilitation options are either not applicable, fully exhausted or unsuccessful.

However, changes to the disability pension system are currently under way. These aim to enhance services, provide significant employment incentives and improve conditions through a more efficient and simpler payment system. The aim is to improve the performance of those who receive a disability pension, simplify the system, reduce income linkages, increase incentives for employment and make the disability pension system more transparent and fairer. Support is also increased for people during their rehabilitation, cooperation between service systems is established and emphasis is placed on preventing people from falling between systems.

Services and support for individuals with disabilities

The Directorate of Labour in Iceland provides specialised services for individuals with disabilities and impaired work capacity. These services are diverse and tailored to the needs of the job seekers aiming to enter or remain in the labour market. They offer supported employment aimed at individuals with reduced work capacity who require assistance with job seeking, job training and maintaining employment. These types of work involve extensive support for those with mental and/or physical disabilities, helping them find suitable employment and providing support in the new workplace. The Directorate of Labour also offers counselling and job search support. Additionally, the Labour Agency is authorised to grant subsidies from the Unemployment Insurance Fund to individuals insured through the fund who participate in labour market activities. The Labour Agency can also enter into agreements with companies or organisations for workplace training of job seekers insured under the unemployment insurance system. The basis of these agreements is an assessment by the Directorate of Labour's consultant that the training will benefit the job seeker in their job search.

Initiatives from The Organisation of the Disabled in Iceland

The Organisation of the Disabled in Iceland (OBI), along with interest groups, associations and local authorities, provides advice and information regarding education and employment opportunities for people with disabilities. OBI also offers various educational opportunities and operates a workplace called Örtækni, which provides disabled individuals with temporary vocational training and/or permanent employment. OBI also facilitates an initiative called Hring sjá, aimed at providing educational and vocational rehabilitation for individuals aged 18 and older who require rehabilitation due to illness, accidents, disabilities or other traumas. The goal is to help these individuals manage studies and pursue employment in the general labour market. The rehabilitation programme includes, for example, individualised studies through short courses or unit-based studies accompanied by specialised advice and support.

6 Norway

In this chapter, we will present Norwegian literature describing MS in relation to labour market participation. A total of four publications are included in this chapter.

We begin with an overview of MS in Norway. Following this introduction, we will discuss relevant employment initiatives and pension schemes available in Norway.

Table 6.1 provides an overview of the included studies from Norway and the themes they focus on. In Norway, two studies mainly focus on income and productivity losses and two focus mainly on labour market attachment. Furthermore, two studies focus on working life as a secondary theme.

Table 6.1 Included studies from Norway by the focus of the study

Study	Labour market attachment	Disability pension and sickness absence	Income and productivity losses	Working life
Svendsen <i>et al.</i> (2018)	X			
Lunde <i>et al.</i> (2014)	X			x
Svendsen <i>et al.</i> (2012)	x		X	
Skogli <i>et al.</i> (2023)	x		X	x

Note: Large and bold X's highlight the primary theme that each study contributes to, which also determines the theme under which the study is presented. Small x's indicate additional themes that the publication further helps to clarify.

6.1 Employment initiatives and pension schemes in Norway

In Norway, a variety of employment initiatives and pension schemes are available to support people with MS in engaging with the Norwegian labour market. The Norwegian Work and Welfare Administration (Arbeids- og velferdsforvaltningen, NAV) manages many initiatives targeted at people with working disabilities.

Sickness benefit

In cases where an employee has a chronic or prolonged illness or disability, NAV can provide sickness benefits during the employer period. This is applicable in situations

where there is a risk of frequent or extraordinarily high absence due to illness over a limited period of time.

Wage subsidy

Wage subsidy is a support scheme where NAV pays part of an employee's wages for a period of time. The aim of this scheme is to help more people retain or secure permanent employment. NAV can grant wage subsidies to both private and public companies. These subsidies can be either temporary or permanent.

Grants for travel or transportation

Grants for travel can be provided instead of sickness benefits if this enables the employee to work either full-time or part-time.

In the case of business or education-related travel, it is possible to receive a grant for taxi transportation if the employee has enduring transportation challenges and, due to these challenges, cannot travel to and from work or education using public transportation.

For individuals with a permanent functional disability who are unable to use public transportation and are already employed or studying, it is possible to apply for a grant for a 'car for work and education' (bil i arbeid og utdanning).

Additionally, allowances are available for necessary extra transportation expenses or car services if these expenses are due to a medical condition.

Supporting arrangements in the workplace

NAV offers a variety of support arrangements in the workplace for employees with disabilities or illnesses. Employees with physical functional disabilities can receive 'functional assistance' in the workplace. The aim of this assistance is to help employees retain or maintain ordinary work by covering expenses for necessary practical help in the workplace. Grants for expert assistance are available to help both employers and employees get neutral expert advice on issues such as work environment and absence due to illness.

The Mentor Grant (mentortilskudd) arrangement allows another employee at the same workplace to be compensated for providing practical assistance, instruction, or guidance to an employee with disabilities or illnesses. This arrangement is often combined with other initiatives such as rehabilitation or wage subsidies.

Rehabilitation

People with MS can apply for a rehabilitation stay to retain or better functional level. Work related rehabilitation (arbeidsrettet rehabilitering) is organised by the

municipalities and the specialised health services. The aim is to help people with health problems to employment or to help them be able to stay in current employment with special arrangements.

Economic benefits

In Norway, various benefits are available depending on the circumstances of the person with a disability:

- **Sickness benefit:** This benefit compensates for lost income for people in active employment who are unable to work due to illness, disability, or injury.
- **Sick leave due to individual days off:** It is possible to receive sick leave for individual days off due to treatment.
- **Work assessment benefit (Arbeidsavklaringspenger (AAP)):** This scheme aims to secure income for people who need to clarify their working capacity due to illness, disability or injury. NAV can assist in clarifying working ability. This option is available for people who have no rights to sickness benefits or who have exhausted their sickness benefit period.
- **Disability benefits (Uføretrygd):** This scheme secures income for people with a permanently reduced working capacity due to illness, disability or injury.

The Norwegian State Educational Loan Fund

The Norwegian State Educational Loan Fund offers various options for students who become ill or have a disability:

- **While Studying:** Students can apply for the conversion of a student loan to a grant if they are sick for more than 2 weeks while studying. If graduation is delayed due to a disability, the student can, in some cases, convert a basic loan to a grant for the additional study period. If a student cannot work part-time or have a summer job due to their disability, it is possible to apply for additional grants.
- **After Graduation:** Graduates can apply for delayed payment or cancelled interest on their student loans. If a person becomes disabled after graduation, they can apply for the cancellation of parts or the entire student loan.

6.2 Labour market attachment

In a study from 2018, Svendsen et al. investigate labour market attachment and the economic costs of multiple sclerosis for the patients and their families in Norway. Data

collection in this study is based on a postal questionnaire sent to MS patients in Hordaland County, western Norway, in 2013–2014. The study finds that 45% of the MS patients who responded to the questionnaire reported, that they had employment. Of these, 14% were partly employed and 31% were fully employed. 12% of the respondents had only primary or lower secondary school, while 34% had upper secondary school. 43% of the respondents had university education (Svendsen et al. 2018).

Lunde *et al.* (2014) investigate demographic and clinical factors associated with employment for individuals with MS. The study is based on data from 213 (90% of all) MS patients in Sogn and Fjordane County in 2010. The patients underwent clinical evaluations, structured interviews and completed surveys. This study finds that 45% of MS patients are employed, with 19% being full-time employed and 26% being part-time employed. The population studied has been diagnosed with MS for 19 years on average. The employment rate decreased with age, with only 33% of male and 32% of female MS patients aged 55-66 employed, compared to 75% of men and 69% of women in the general population. The study finds that a lower age at onset of MS was independently associated with higher employment. MS patients currently working were approximately 3 years younger at onset of the disease than people with MS that were unemployed. Furthermore, the employed MS patients were on average 10 years younger than the unemployed MS patients.

Lunde *et al.* (2014) also show a significant difference in full-time employment based on different types of MS: 66% of patients with RRMS were in employment (either full- or part-time) compared to 24% of patients with SPMS and 15% of those with PPMS. These differences align with other studies concluding that patients with RRMS had lower disability levels and experience a less progressive type of MS⁶. The study also indicates significant variation in employment rates between patients with different EDSS scores, with MS patients having lower scores showing higher employment rates.

Furthermore Lunde *et al.* (2014) reveal that patients with higher levels of education have higher employment rates. Specifically, 57% of MS patients with higher education are employed, compared to 40% of patients with lower education. The authors suggest that the onset of chronic illness at an early age typically disrupts the education process, leading to less education among these patients. However, since MS onset usually occurs between the ages of 20 and 40, patients often have had time to complete their education before onset. Higher education was associated with better job opportunities, a greater likelihood of being employed, higher wages and better job benefits, which might explain some of the differences between individuals with and without higher education. However, the study does not indicate that the type of

⁶ Studies from France and USA.

education (physically demanding versus less physically demanding jobs) influenced employment status among MS patients.

The study also finds that less severe fatigue was independently associated with higher employment. Other studies have identified fatigue as a common factor leading to early exit from the workforce and playing a significant role in changes in occupational status (Lunde et al. 2014).

6.3 Income and productivity losses

Svendsen *et al.* (2012) conducted a study to assess the annual economic costs of MS on the Norwegian society, examining costs, illness severity and quality of life. The study utilised a cost-of-illness analysis based on aggregated diagnostic data, national statistics, registries and direct patient information obtained from a sample of patients in 2002. Work participation data were sourced from national registries, while patient quality of life was assessed through a questionnaire sent to 526 MS patients in Hordaland County, with an 80% response rate.

The findings showed that among the respondents, 34% were employed while 66% were unemployed. The total cost of MS to Norwegian society in 2002 was estimated at €439 million. A significant portion of these costs, 61%, were attributed to indirect economic factors resulting from reduced participation in paid work. This reduction encompassed short-term sick leave due to acute disease activity, long-term sick leave due to disease progression, stays in rehabilitation centres, reduced working hours, early retirement and premature death (Svendsen et al. 2018).

Svendsen *et al.* (2018) find that the primary contributors to these costs were early retirement and reduced working hours, with 50% of respondents being fully retired and 14% experiencing reduced working hours, resulting in an average workload reduction of 52%. The study compared the cost of reduced work participation in Norway with that in Sweden, showing higher costs in Norway. This disparity was largely due to Norway's higher rates of full-time retirement, which were more than 40% higher than those observed in Sweden.

In 2023, Menon Economics published a report investigating the societal costs of MS in Norway. The report is based on a literature review, statistics from the Norwegian MS Society's registries, feedback sessions and interviews with individuals with MS, informal caregivers and clinicians. The study finds that productivity loss due to reduced working capacity, presenteeism and tax costs constitutes 46% of the total social costs. However, there is significant variation among individuals affected by the disease in relation to productivity costs (Skogli et al. 2023).

In Menon's calculation of productivity losses, it is assumed that 55% of individuals with MS between the ages of 20 and 64 are in employment, including 40% in full-time jobs and 60% with reduced working hours. The reduced working capacity is mainly due to fatigue. MS causes a high loss of productivity because the illness affects younger persons in their working years and because fatigue is a widespread symptom with very few effective treatments. Other reasons for reduced productivity include movement challenges, cognitive symptoms and visual disturbances. For individuals in employment, shorter periods of absence due to treatment or doctor's appointments may reduce productivity. However, MS affects individuals differently and working capacity may vary. For some people, MS is severe, causing an inability to work. Others may require adjustments in work tasks, while some have relatively mild disease courses, causing minimal functional impairment and allowing them to work full-time. Working capacity may therefore vary for the individual. The study points out that a stable illness, office or sedentary work, medical treatment and flexible working hours are factors contributing to the individual remaining an active part of the workforce.

7 Sweden

In this chapter, we will present literature describing labour market participation and MS in Sweden. A total of eight publications are included.

The chapter begins with a short description of MS in Sweden. Following this, relevant Swedish employment initiatives and pension schemes are presented.

In Table 7.1, we provide an overview of the included studies from Sweden and how they are distributed on the identified themes. In Sweden, five studies mainly focus on disability pension and sickness absence and two focus on income and productivity losses. One of the included studies focuses on labour market attachment.

Table 7.1 Included studies from Sweden by the focus of the study

Study	Labour market attachment	Disability pension and sickness absence	Income and productivity losses	Working life
Landfeldt <i>et al.</i> (2018)			X	
Brundin <i>et al.</i> (2017)	X			
Murley, Tinghög <i>et al.</i> (2020)		X		
Machado <i>et al.</i> (2022)		X		
Landfeldt <i>et al.</i> (2016)		X		
Murley, Karampampa <i>et al.</i> (2020)		X		
Castelo-Branco <i>et al.</i> (2019)		X		
Kavaliunas <i>et al.</i> (2017)			X	

Note: Large and bold **X**'s highlight the primary theme that each study contributes to, which also determines the theme under which the study is presented. Small x's indicate additional themes that the publication further helps to clarify.

7.1 Employment initiatives and pension schemes in Sweden

In Sweden, a range of employment initiatives and pensions schemes are available for individuals with MS and other disabilities that affect their ability to participate in the labour market.

The Swedish Work Environment Authority (Arbetsmiljöverket), a regulatory authority in Sweden, has compiled guidelines for people to be able to continue working after illness or disability. The foundation of work adaptation is that the employer must modify work tasks and the work environment as much as is necessary for the employee to be able to continue performing their work tasks. However, each workplace and task cannot always be adapted in the way that is desired, depending on the conditions of the business. Individual adaptations in the workplace can help people with MS achieve more equal working conditions. This can include modifying work environment or equipment, allowing flexible schedules or reducing working hours. The type of occupation plays a significant role in determining sickness absence and eligibility for sickness or activity compensation for people with MS.

Neurological rehabilitation

Neurological rehabilitation is also available for people with MS. The purpose of rehabilitations is to restore and retain abilities, including physical, behavioural, cognitive and psychological skills. Rehabilitation can help individuals learn compensatory strategies for lost abilities, supporting them in maintaining a high-functioning everyday life. Rehabilitation can also provide help to learn how to use different assistance devices, aids or home adaptations. Accordingly, various types of *assistive devices*, such as mobility aids, home assistive aids or equipment for leisure activities are available. These devices can contribute to an easier everyday life or help maintain participation in working life.

Benefits in relations to sickness

When a person becomes sick, they can receive sickness benefit for 90 days if they are unable to perform their usual work or other temporary work. In this case, the Social Insurance (Försäkringskassan), which pays the sick pay, will assess the individual's ability to work, not the illness itself. After 90 days, the individual is still entitled to sick pay if they cannot perform any work at all. The social insurance may then offer a meeting with the Employment Agency (Arbetsförmedlingen) to provide more information on how to proceed. This option is available in the first 180 days of the sick leave period. After this period, the individual is entitled to a sickness allowance if they cannot work in the regular labour market.

If a person needs to refrain from work due to medical treatment or rehabilitation, they can receive preventive sickness pay from the Social Insurance. The purpose of the treatment or rehabilitation must be to prevent or shorten the illness, aiming to help the person return to work. Preventive sickness pay is just under 80% of the persons income. However, the maximum amount is SEK 1,218 per day for 7 days a week before tax.

Sickness allowance can be granted to individuals who are likely to never to be able to work due to an illness, injury or disability. The individual must have a permanent reduction in working ability and be between 30 and 64 years old. The sickness allowance can be granted at 25%, 50%, 75% or 100%, depending on the reduction of working capacity. This allowance is granted until further notice. However, a new assessment of the working ability must be carried out every 3 year according to the law.

Personal assistance

The Act on Support and Services for certain disabled persons entitles individuals with major disabilities to various types of support, including personal assistance. To receive personal assistance, the individual must need help with one or more of the following basic needs: 1) personal hygiene 2) meals 3) dressing 4) communication or 5) other help that requires in-depth knowledge of the disability. The type of personal assistance provided is based on the individual's needs and might include support to enable the person to work. There is an upper age limit of 65 years to be eligible for personal assistance.

Transportation

If an individual has difficulties getting around or using public transportation due to MS, they can be granted a transport service. Anyone with a non-temporary disability that prevents them from moving around or using public transportation is entitled to this service. This service allows individuals to travel by taxi or special vehicle and includes, for example, transportation to and from their workplace.

7.2 Labour market attachment

Brundin *et al.* (2017) investigate work capacity for MS patients in Sweden. 1,864 persons participated in the survey. They find that among the respondents in the working age, 55% are employed. 22% of those who are employed are working full time. Among the patients in the working age, 37% is not working due to MS.

The employment rate decreases dramatically with the severity of MS. Patients with and EDSS score from 0-3 have an employment rate of 78%, while the rate is 37% for patients with an EDSS score from 4-6.5. For patients with severe MS and an EDSS score from 7-9, the employment rate is 13%.

7.3 Disability pension and sickness absence

A study by Landfeldt *et al.* (2016) investigates sick leave and disability pension before and after MS diagnosis based on nationwide register data. The study finds that sick leave and disability pension rates are markedly higher among people with MS compared to the general population. Statistically significant differences were observed 15 years before the MS diagnosis for sick leave and 3 years before for disability pension in contrast to the general population. Additionally, people with MS had on average 36 additional sick leave days and 43 additional disability pension days per year compared to general population controls. Nearly 8 out of 10 patients with MS were either partially or fully absent from the labour force within a decade after diagnosis. Of these, nearly 4 out of 10 were on full-time disability pension within a decade, at a mean age of 43 years, with only a minor proportion returning to the labour force.

The study also finds that both sick leave and disability pension rates are significantly higher among women than men and that married individuals with MS had higher risks of sick leave.

Murley, Karampampa *et al.* (2020) explore diagnosis-specific sickness absence and disability pension before and after an MS diagnosis compared to a reference group. The study is based on an 8-year longitudinal nationwide cohort study. It shows that people with MS have higher rates of sickness absence and disability pension than the general population. However, these are not solely due to the MS diagnosis. The mean difference in all-cause sickness absence or disability pension days is 10.3 more for patients with MS than the reference group after 4 years, with the difference peaking 1 year after diagnosis at an average of 70 days more among MS patients compared to the reference group.

Regarding sickness absence, Murley, Tinghög *et al.* (2020) find that 1 year before diagnosis, 35% of MS patients had some sick leave, compared to 9.5% of the reference group. The estimated difference in proportions of individuals on all-cause sickness absence 1 year before diagnosis was 25 percentage points higher for MS patients than for the reference group, increasing to 34 percentage points 1 year after diagnosis, and then decreasing to 17 percentage points 4 years after diagnosis. This indicates that sickness absence peaks around the time of MS diagnosis. However, in the first year after diagnosis, only 46% of the sickness absence days among MS patients were due to MS.

The progression of individuals on disability pension vary among individuals. 4 years before diagnosis, the proportions of individuals on all-cause disability pension was 2 percentage points higher for MS patients than for the reference group, increasing to 19 percentage points 4 years after diagnosis. The mean proportion of disability

pension days due to MS diagnosis increases from 13% 1 year after to 55% 4 years after diagnosis.

Castelo-Branco *et al.* (2019) aim to assess the long-term consequences of different types of MS (RRMS, SPMS and PPMS) on sick leave and disability pension. This retrospective, longitudinal cohort study uses data from national registers. In line with Murley, Karampampa *et al.*'s findings, this study shows that the average annual number of sick leave days reaches its peak around the time of diagnosis. Disability pension days increase until retirement age. The study finds that patients with RRMS had substantially less labour-force absenteeism than patients with SPMS or PPMS. However, the study found no significant differences in absenteeism or full-time disability pension between patients with SPMS and PPMS. For RRMS, the mean number of days with sick leave and disability pension combined ranged from 101 days (1 year after diagnosis) to 164 days (11 years after diagnosis). Corresponding estimates for PPMS were 188 and 311 days. When adjusting for different confounders, the mean annual difference was predicted as 82 days, ranging from 42 days (1 year after diagnosis) to 100 days (8 years after diagnosis). The study also shows that individuals diagnosed with PPMS have more days with sick leave and disability pension both before and after diagnosis. This difference is statistically significant up to 10 years before diagnosis.

Another study by Murley, Tinghög *et al.* (2020) investigates activity and sickness absence or disability pension among working-aged people with MS. The study is a nationwide register-based cohort study from 1 year prior to 5 years after diagnosis. It identifies six different working-life sequences, representing the most common patterns of activity, sickness absence and disability pension over time.

The most common working-life sequence identified in this study is defined as 'Stable High Activity', represented by 48% of people with MS. This sequence is characterised by a stable activity state throughout the study period. 17% had 'unstable medium activity', characterised by sickness absence or disability pension proximate to the time of diagnosis combined with mixed activity afterwards. 'Stable high sickness absence/disability pension', characterised by high extent of sickness absence/disability pension throughout the period, constituted 15% of the population (Murley, Tinghög *et al.*, 2020).

Murley, Tinghög *et al.* (2020) also found that people with MS did not only progress from activity to full-time sickness absence/disability pension. Some people had sickness absence/disability pension around the time of diagnosis but returned to activity later on. Returns to activity were mostly observed after sickness absence/disability pension close to MS diagnosis, indicating that people with MS may have temporarily reduced working capacity but can return to work later.

Demographic characteristics among the patients varied across the different working-life sequences. Women, older people and patients with lower levels of education were associated with a higher extent of sickness absence or disability pension. People in manual labour had higher odds of having unstable working activity or stable high sickness absence/disability pension sequences compared with office workers (Murley, Tinghög *et al.*, 2020).

A recent study by Machado *et al.* (2022) investigates the distribution of self-employment and other types of employment before and after an MS diagnosis, as well as how different types of employment are associated with sickness absence and disability pension. The study is based on a longitudinal cohort study over 6 years of people diagnosed with MS and individuals without MS. It finds that people with MS have more employment status transitions than the reference group in the period before and shortly after diagnosis, with most transitions being from working to non-working status. Transitions to self-employment were not widespread among people recently diagnosed with MS.

Furthermore, the study finds that transitions to another employment status do not influence the risk of long-term sickness absence or disability pension. All employment status groups had a higher risk of sickness absence or disability pension around the time of diagnosis compared to the reference group. Self-employed people with MS did not have a higher risk of sickness absence or disability pension than employed people with MS. However, the study also showed that the majority of newly diagnosed people with MS had no sickness absence or disability pension.

7.4 Income and productivity losses

A study by Landfeldt *et al.* (2018) investigates personal income before and after the diagnosis of MS. The study is based on data from a nationwide, disease-specific register with general population controls. Mean income per year before and after diagnosis was assessed based on data from national registers. This study finds no significant difference in income between MS patients and controls at any year before disease onset. However, after diagnosis, patients with MS had an average of €5,130 less gross salary per year compared with controls. On average for people with MS, the loss of gross salary was €2,430 in the first year and €9,010 after 11 years.

The cumulative loss of disposable income during the first 10 years after diagnosis was similar between men and women. However, a significant reduction in income was observed after 5 years for women and after 9 years for men. Accordingly, women with MS had a 37% higher risk of having zero salary after diagnosis compared with controls, while men had a 50% higher risk. Having a university degree at the time of

diagnosis (for both sexes) and being married (for men) was associated with significantly higher income. For women with MS, factors such as EDSS score, anxiety/depression, pain and insomnia were associated with significantly lower income, while for men with MS, only the EDSS score and anxiety showed significant results.

The study noted only minor differences between patients with MS and controls when comparing mean annual disposable income (salary from work and transfers, e.g. social benefits). This indicates that even though many patients lose the ability to support themselves financially through regular employment, they still have a relatively high disposable income due to social transfers (Landfeldt et al. 2018).

Kavaliunas *et al.* investigate the relationship between income and cognitive function among people with MS in a cross-sectional study linking data from three national registers. They find that average income (including earnings, disability pension, sickness absence, disability allowance, unemployment compensation and social assistance) decreases with lower cognitive function. Among patients with higher cognitive function, 89% of the income is based on earnings, compared to 54% among those with lower cognitive function. MS patients with higher cognitive function also earned more than twice as much as those with lower cognitive function. The chance of receiving salary earnings was 40% higher among people with higher cognitive function, while the risk of relying on benefits was 19% lower.

➤ **Supporting Material**

8 Methods

This study is designed as a literature search, gathering the existing knowledge about MS and the labour market. The search has been aimed at different labour market outcomes such as labour market attachment, different types of employment, unemployment, social benefits and retirement age.

VIVE has been planning and facilitating the overall project, and the literature search has been conducted by MS Societies from each of the Nordic countries. Each MS Society has been responsible for the literature search in their own respective language and providing summaries of each publication in English. Accordingly, the individual MS Societies have provided information about employment initiatives and schemes they consider relevant for people with MS in their respective country. These descriptions constitute the basis of the sections about 'employment initiatives and pension schemes', opening each of the chapters about the Nordic countries.

VIVE coordinated and guided the literature search. Afterwards, VIVE was responsible for the quality check of each publication as well as the analysis and presentation of the gathered materials.

8.1 Inclusion criteria

For the studies to be included in the literature review, they had to meet a set of criteria that we had established in advance. The topics we initially aimed to explore were:

- Proportion of individuals with MS in and outside the labour market
 - Degree of work participation
 - Conditions/programmes for alternative employment forms
- Timing of retirement for people with MS
 - Pension and retirement types
 - Reasons for retirement/job changes
- Effects of interventions targeted at individuals with MS on work participation and retirement

The inclusion criteria of this study can be found in table 8.1.

Table 8.1 Inclusion criteria

Subject	Inclusion criteria
Themes	Labour market attachment for people with MS Sick leave and disability pension for people with MS Income and productivity losses Working life and symptoms affecting working life for people with MS
Country	Denmark, Finland, Iceland, Norway, Sweden
Language	Danish, Finnish, Icelandic, Norwegian, Swedish, English
Year of publication	2000-2024
Type of publication	Research literature, e.g. research articles, books, book sections or chapters Grey literature, e.g. reports, studies conducted by authorities, organisations, NGOs etc., open access statistics
Type of data	Quantitative data, e.g. register data or survey data (Additional data types, e.g. qualitative data, may be included)

8.2 Literature search

Each of the Nordic countries has conducted an explorative literature search concerning MS and the labour market covering publications from their own country. The searches have been conducted in English and the Nordic languages. It has been up to the individual MS Societies how they conducted their search.

Prior to the literature search, the Nordic MS Societies attended a joint introduction meeting to ensure a common understanding of the project aims and procedure. After the introduction meeting, VIVE sent an elaborated information note to further clarify project aims and provide guidelines on how to conduct the literature search. The guideline included information on inclusion criteria (described above), suggested keywords (Boks 8.1) and recommendations on where and how to search.

Boks 8.1 Suggested English keywords

- Multiple sclerosis, MS, Sclerosis
- Labour market, labour market affiliation, labour market attachment, employment, employment relationship, forms of employment, labour, job, work
- Unemployment, pension, retirement, early retirement, flex job, sickness benefits, job change, transition
- Recruitment, retention, support, benefits, initiatives, schemes, interventions
- Study, report, survey, review, analysis, research, register data, natural experiment

VIVE recommended searching for scientific publications in research databases, libraries and Google Scholar. Recommendations for searching for grey literature included visiting the webpages of national authorities, organisations, NGOs, research centres and statistical bureaus. Additionally, using the snowballing technique is recommended as an effective search method to track down relevant publications using the reference list or authors' names from already identified literature.

It is also expected that some of the MS Societies might already be aware of relevant literature from networks or previous collaborations. This literature could also be included in the knowledge gathering.

During the search period, the MS Societies have had the opportunity for guidance and support from employees at VIVE. However, the extent of each country's literature search ultimately depended on the MS Societies' resources and competencies resulting in variations in the depth and scope of their searches.

The extent of each society's literature search ultimately depended on their resources, competencies and prior knowledge of analyses. Consequently, there may be variations in the depth and scope of the searches. Therefore, the literature search cannot be considered exhaustive. This means that we cannot with certainty claim that no literature exists in an area we have identified as a knowledge gap. However, a substantial amount of relevant literature has been collected, and we therefore believe that there is not much literature available on the identified areas.

8.3 Screening of literature

The literature search across the Nordic countries yielded a total of 44 findings submitted to VIVE. The literature is divided among the Nordic countries as follows:

- Denmark: 12
- Finland: 12
- Iceland: 2
- Norway: 4
- Sweden: 14

Initially, the literature was screened by title and abstract only, resulting in 17 publications discarded due to not matching the inclusion criteria. The publications were then subjected to screening based on result and conclusions, resulting in 26 relevant publications. Studies were excluded if they did not meet the inclusion criteria. Additionally, 2 studies on MS and working life, known by VIVE prior to the literature search, were added to the included literature. After this screening, publications included in the final report are divided among the Nordic countries as follows:

- Denmark: 12
- Finland: 4
- Iceland: 0
- Norway: 4
- Sweden: 8

Thus, we have included a number of studies from all the Nordic countries except Iceland. At the same time, the studies were to some degree distributed across the pre-selected themes.

8.4 Analysis of literature

From the gathered publications, we identified four themes that the studies focused on. The themes were initially based on the research questions and were refined according to the findings from the identified literature. The main themes presented in this report are: labour market attachment, disability pension and sickness absence, income and productivity losses, and working life and symptoms affecting working life among people with MS.

However, the findings of this literature search are organised in chapters based on national affiliation. This structure was chosen to provide greater clarity and to make understanding of the legal context relevant to each study easier. In Chapter 2, the

studies are compared across countries, based on the themes outlined in the report. Table 8.2 presents the themes and their representation in the literature from each country.

Table 8.2 Number of studies by country and theme

Country	Labour market attachment	Disability pension and sickness absence	Income and productivity loss	Working life
Denmark	1	5	2	4
Finland	0	1	2	1
Iceland	0	0	0	0
Norway	2	0	2	0
Sweden	1	5	2	0
<i>In total</i>	4	11	8	5

We have included studies from most of the themes we had selected in advance which we aimed to cover with this literature review. However, no effect studies of interventions directly targeting people with MS and their labour market attachment were found, which was a theme we had hoped to address.

Confidence intervals

Not all the studies report confidence intervals of the employment rate. In these, we calculate them as cases and we calculate the standard errors as

$$CI = \bar{x} \pm Z \cdot SE$$

where \bar{x} is the employment rate and SE is the standard error and Z is the confidence level value, which in this case is set to 1.96, corresponding to a significance level of 95%.

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