



# Reducing Health Inequalities: The Role of Civil Society

Kirsty Doyle, Timon Forster, Alexander Kentikelenis,  
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# Foreword

# Foreword

For all of us, and our families, health is a most important issue in our life. It is considered to be a basic human need. However, it has always remained a marginal one among the responsibilities of the European Union. Some even question why the European Commission needs a health portfolio at all, since this policy field is often linked to the concept of subsidiarity: national health insurance and care systems and local delivery structures.

On the other hand, the developments of the recent years allow for a new approach, and perhaps even necessitate a reconsideration of conventional wisdom. In 2017, the EU leaders endorsed the European Pillar of Social Rights (EPSR), which is about delivering new and more effective rights for citizens and creating guarantees for the old ones. The Pillar has 20 key principles, structured into three main categories: equal opportunities and access to the labour market, fair working conditions, and social protection and inclusion.

Health is included under the social protection and inclusion chapter of the EPSR. Specifically, the Pillar states that 'everyone has the right to timely access to affordable, preventive and curative health care of good quality'. While appearing among the themes of the Pillar, the role of the EU in health policy remains restricted to setting the policy framework and providing direction to Member States.

While Member States are best situated to reducing health inequalities within their health system, this report highlights the unique contribution of civil society. As outlined in the report, civil society organisations were established to fulfil two main objectives. The first was to provide services that were not adequately supplied by the public health system, while the second was to hold the state to account for the lack of service. While they face a number of challenges, the report shows that civil society can have a significant role in reducing health inequalities.

Furthermore, the report demonstrates the importance of EU funding to civil society. This support of civil society by the EU sustains democratic accountability and supports civic engagement at a local and national level, which in turn contributes to the practice and understanding of European citizenship.

For the first time in its history, a medical doctor has been elected to be President of the European Commission. It is high time for the EU to make a clear commitment to reducing health inequalities. The studies in this volume, together with country specific recommendations, help make a strong case for that purpose.

László Andor

Secretary General, FEPS



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# Acknowledgements

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# Executive Summary

# Executive Summary

## Introduction

This report examines the inequalities in access to healthcare services and explores the role that civil society organisations (CSOs) play in reducing these health inequalities. The role of CSOs is emphasised in the report as it serves as an indicator of where the state is failing in relation to healthcare. Using a case study approach, the report provides a comparative analysis of access to diagnostic services in Ireland, Germany and Spain – three European countries with different health systems. The three case study conditions are autism spectrum disorder, lung cancer and brain tumours. The focus on diagnostic services was selected because access to diagnosis is crucial to surviving life threatening illnesses (lung cancer and brain tumours) and essential for improving life trajectories for those with developmental conditions (autism spectrum disorder).

The findings from the report are based on three research methods:

1. Analysis of relevant policy documents in each of the case study countries.
2. Semi-structured interviews with CSOs, healthcare professionals and policy makers in each of the case studies countries.
3. Roundtable events in Ireland and Spain with members from relevant CSOs and policy makers who were invited to provide feedback on the initial findings of the study and contribute to policy recommendations.

## Health Systems and Health Inequalities

Ireland, Spain and Germany have contrasting types of health systems, which is significant in relation to healthcare coverage and access. Eligibility to healthcare in Ireland is not universal and is based primarily on residency and means. Conversely, Spain has a National Health Service and German healthcare operates through a Social Insurance System which both provide almost universal coverage.

This report finds that in countries where healthcare coverage is almost universal – Spain and Germany – there were geographical inequalities in access to lung cancer and brain tumour diagnostics rather than inequalities based on socio-economic background. On the other hand, healthcare inequalities in Ireland are very much rooted in socio-economic factors. The ability to pay privately to access lung cancer and brain tumour diagnosis results in important differences between Ireland and Spain/Germany. At the same time, this report underlines an important commonality between all three countries in relation to inequalities when accessing an autism diagnosis. The research finds that there is no clear pathway to diagnosis in Ireland, Spain or Germany.

## The Role of Civil Society in Reducing Health Inequalities

Civil society organisations reduce health inequalities in two ways: directly through service provision and indirectly by influencing policy. With regards to service provision, the capacity of CSOs to reduce health inequalities was significant in all three countries. Autism, lung cancer and brain tumour CSOs in Ireland, Spain and Germany reduce health inequalities by providing services directly to patients and their families. In terms of policy, size of the organisation was an indicator of whether or not the CSOs had any impact. CSOs in Germany were found to have the most significant impact on policy due to the formal structures within the German health system that facilitate communication with policymakers and engagement with the legislative process.

## Reducing Health Inequalities: The Role of the EU

In terms of health, the main role of the EU is to provide direction to Member States in order to increase access to healthcare, reduce inequalities and create sustainable health systems. In addition to this, EU institutions also build cooperation between Member States for cross-border issues, such as those relating to the free movement of goods, services and people. Nevertheless, while the EU institutions set the framework and provide direction, most of the tools to reduce health inequalities are in the hands of Member States, social partners and civil society. Findings from this report indicate that in order for civil society to continue having an effective role in reducing health inequalities, further support from the EU is needed including improved and simplified access to EU funding and grants.

## Conclusion and Recommendations

**The report makes the following country-specific recommendations:**

### Ireland

- Establish a universal, single tier health service based around the principles of timely access and care driven by need rather than the ability to pay.
- Provide clear pathways to diagnostic services and therapies for people with autism.
- Ensure policies to improve access to diagnostic services and therapies for people with autism are fully implemented and resourced.
- Moderate geographic variation in access to diagnostic services.
- Reduce waiting times for first outpatient department appointment in the case of brain tumour diagnoses.
- Improve access to funding for CSOs. Specifically, provide access to multi-annual funding.
- Develop a formal and transparent framework through which CSOs participate in policy development and implementation strategies.
- Promote increased engagement and representation among organisations within the civil society sector.

## Germany

- Moderate geographic variation in access to health services.
- Increase investment in training of medical staff to address the shortage of key personnel in diagnostic services.
- Spend more resources on campaigns to disseminate information on health challenges and conditions to reduce stigma from the public and the media.
- Reduce the complexity of the German health system to lower inequalities due to health literacy.
- Extend representation of German CSOs in the governance of the German health system by giving them voting rights to ensure that the patients' interests are at the heart of health policy reforms.
- Facilitate access to funding for CSOs, tailoring the application and disbursement processes to the needs and resources of CSOs.

## Spain

- Dedicate more research funding to estimate the prevalence of autism and mortality rates for cancer.
- Address regional inequalities by standardising the provision of treatment and available diagnostic tools for both autism and cancer across all regions.
- Improve organisation of cancer services to ensure that patients can receive the treatment they need in one health care facility rather than having to attend multiple locations to receive treatment.
- Provide public autism services with a multidisciplinary team and make sure appropriate follow-up and continuous care are provided.
- Take into consideration patients' extra costs incurred when living with cancer or autism and provide assistance when needed.
- Take into account gender inequalities in the prevention and treatment for both cancer and autism.
- Overall, there is a need to improve the organisation of oncological and autism diagnosis and care; coordinate the different specialists needed; and coordinate the different levels of care and follow-up.
- CSOs are providing key services for people living with cancer and autism and these organisations need to be appropriately supported.
- CSOs have been involved in the Spanish strategies to address autism and cancer. There is a need to include them in the monitoring and evaluating processes.
- Ensure that CSOs are not prohibited by government funding from engaging in advocacy or experience any repercussions for critiquing policy.
- Design better pathways and involve CSOs in the design, implementation and evaluation of policies.
- Review funding disbursements from the national to the regional level to ensure that fundamental programmes are not lost when policies and processes change.

### **The report also makes the following EU recommendations:**

- Full implementation of the European Pillar of Social Rights.
- Improved and simplified access to EU funding and grants.

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# 1. Introduction

# 1. Introduction

Over the past decade, there has been growing awareness of health inequalities – the unjust and avoidable differences in health. In 2008, the Commission on Social Determinants of Health highlighted that the circumstances within which people grow, live, work, and age influences their overall health, as well as their access to and experiences of healthcare services.

Following this ground-breaking report, the WHO published the Review of social determinants and the health divide in the WHO European Region in 2013. This Review was commissioned to support the development of the new European policy framework, Health 2020<sup>1</sup>. The Review grouped its recommendations to promote health equity within and between countries under four themes, with the starting point being the 'health system'. It outlined that universal access to healthcare is a priority as although there have been remarkable gains in health, these have not been shared equally across the European region and in many countries, health inequalities are actually increasing.

These findings were supported by FEPS-TASC's recent report 'Health Inequalities in Europe: Setting the Stage for Progressive Policy Action'. This report explored various determinants of health inequalities including health systems and found that variations in financing, resources and coverage of healthcare can either narrow or widen health inequalities. Like the WHO publications<sup>2</sup>, this report recommends that countries should provide universal healthcare coverage in order to promote equal access and utilisation of health services.

The call for universal access to affordable healthcare services has also been echoed at European and international levels. At the international level, the United Nation's Sustainable Development Goals have called for universal access to affordable healthcare services to help address health inequalities between and within nations. Likewise, at the European level, the European Pillar of Social Rights states that everybody has the right to timely access of affordable healthcare services.

With health inequalities now on the European and international agenda, there is an opportunity to make real progress in terms of developing progressive healthcare policies that support greater equality of access.

This FEPS-TASC report on reducing health inequalities aims to contribute to this policy agenda by examining the inequalities in access to healthcare services in three European countries and outlining the role of civil society organisations (CSOs) in reducing these inequalities.

## *Case Studies*

In order to gain in-depth information on the inequalities people face when accessing healthcare services, three case study conditions were selected for analysis – lung cancer, brain tumours and autism spectrum disorder. These conditions were chosen as they enable a comparison in healthcare access between common and rare cancer types (lung cancer is a common cancer and one of the leading causes of death worldwide<sup>3</sup> - in comparison, brain tumours are considered a rare cancer type) and between life threatening illnesses and developmental disorders.

Specifically, the report compares inequalities in access to diagnostic services for these health conditions.



This focus is important as timely access to diagnosis is essential to surviving life threatening illnesses (such as lung cancer and brain tumours) and to improving life trajectories for those with developmental conditions (such as autism spectrum disorder).

### ***Civil Society Organisations***

As well as identifying and comparing inequalities in access to diagnostic services for the three health conditions, the report also outlines the role that CSOs have in reducing these inequalities. This is a significant feature of the report as civil society organisations tend to establish in response to a need for services which are not adequately provided by the state. As such, the role of CSOs in this report serves as an indicator of where the state is failing in relation to healthcare access for the three case study conditions.

### ***Country Comparison***

The research for this report was carried out in three European countries with different types of health systems – Ireland, Germany and Spain. Germany has a Social Health Insurance System, while Spain has a National Health System (NHS). In comparison, Ireland's health care system is two-tier, with both public and private sectors.

By comparing inequalities in access to services across the different health systems, the report highlights which health system is most equitable in terms of healthcare access. In addition, the country comparison also enables the report to outline the conditions within which CSOs are most effective in terms of reducing inequalities and influencing health policy.

### ***Methodology***

The data analysed in this report was collected using three principal research methods. First, a review of relevant policy documents was carried out in each of the case study countries. Second, semi-structured interviews were conducted with civil society organisations, healthcare professionals and policy makers across the three countries. Third, roundtable events were held in both Ireland and Spain. At these events, members from relevant civil society organisations and policy makers were invited to provide feedback on the initial findings of the study and to contribute to policy recommendations. More details on methodology can be found in Appendix 1.

### ***Structure of the Report***

The report is structured as follows. Chapter 2 provides an overview of the health systems in each of the countries – Ireland, Germany and Spain – and outlines the inequalities in access to diagnostic services for the three case study conditions. Chapter 3 discusses the role of CSOs in reducing health inequalities. It outlines the number of organisations there are for each of the case study conditions, how they are financed, the services they provide and the impact they have. Chapter 4 provides a brief overview of EU health policies and outlines the role that they have in reducing health inequalities. The report concludes with Chapter 5, which summarises the main findings of the report and makes recommendations to reduce health inequalities and strengthen civil society in each of the case study countries as well as across the EU.



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# 2. Health Systems and Health Inequalities

## 2. Health Systems and Health Inequalities

### *2.1 Chapter Summary*

- This chapter provides an overview of the health systems in Ireland, Germany and Spain. Each of these three European countries has a contrasting type of health system, which is significant in relation to healthcare coverage and access.
- Eligibility to healthcare in Ireland is not universal and is based primarily on residency and means. In contrast, Spain has a National Health Service and German healthcare operates through a Social Insurance System which both provide almost universal coverage.
- In addition to providing an overview of the three differing health systems, this chapter examines health inequalities within each of the health systems. This was addressed through a case study approach, focusing on access to diagnosis and services for three conditions: autism spectrum disorder, lung cancer and brain tumours.
- In Germany and Spain, where healthcare coverage is almost universal, the main inequalities in relation to access to diagnosis for lung cancer and brain tumours were geographical.
- In comparison, in Ireland, inequalities in access to diagnostic services are both geographical and socio-economic.
- In contrast to the cancer case studies, the experiences of accessing diagnostic services for autism were similar across the three countries. Participants in all countries found it difficult to navigate the assessment process and reported wait times of up to 2 years.
- The findings from this chapter suggest that health systems with universal coverage reduce inequalities based on socio-economic grounds for certain conditions, such as cancer.
- For complex conditions such as autism, the type of health system was not a significant factor in reducing inequalities. Rather, the ability to pay to access services privately as well as 'health literacy'—the knowledge of how to navigate the health system— contributes significantly to socio-economic inequalities.

### *2.2 Chapter Outline*

This chapter discusses inequalities within the health systems of three European countries – Ireland, Germany and Spain. Taking each country in turn, it provides an overview of the health systems, including the governance structures in place, how the systems are funded, as well as information on healthcare eligibility. Drawing on examples from the case study conditions – lung cancer, brain tumour, and autism – it then highlights inequalities in access to diagnostic services in each of the countries. The chapter concludes by summarising significant similarities and differences between the three countries.

## 2.3 Ireland

### The Irish Health System

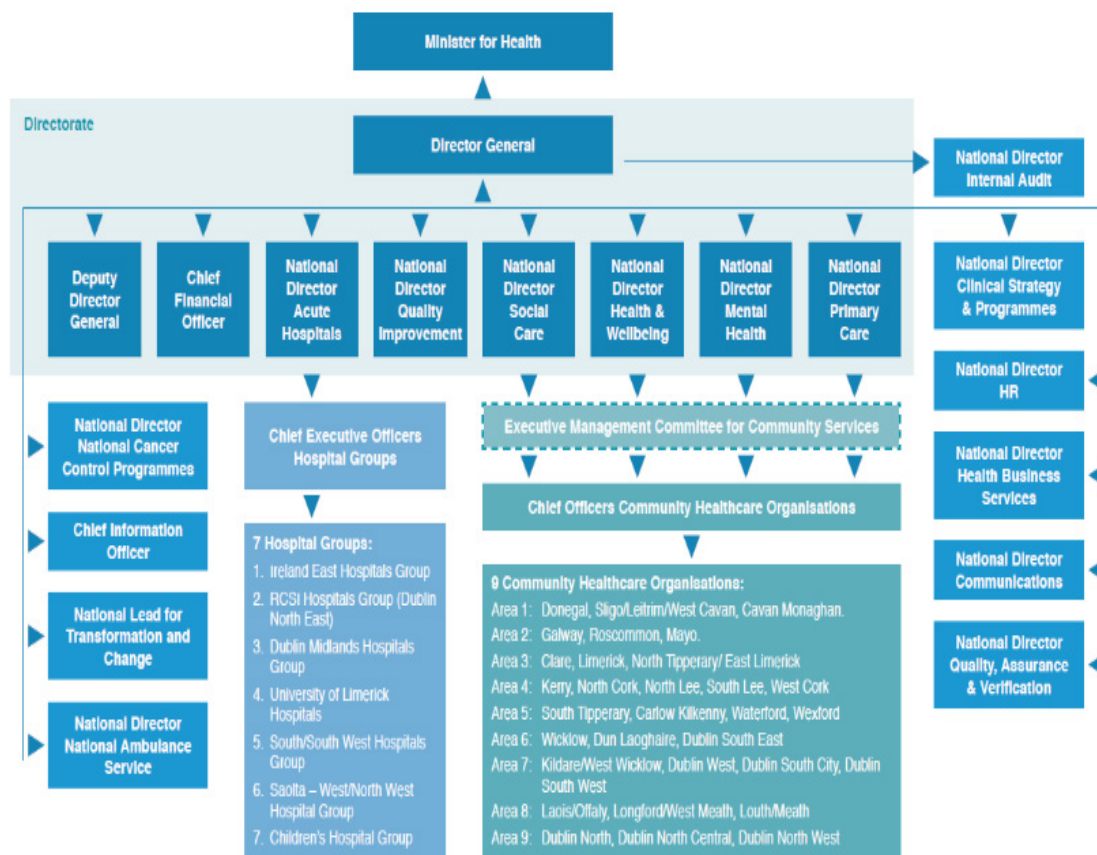
The Irish health system is characterised by a complex mixture of public, private and voluntary healthcare provision, which stems from the historical development of healthcare in Ireland. For instance, charitable and religious organisations had a significant role in providing healthcare to the sick and poor, particularly in the primary care sector. In addition, throughout the 18th and 19th centuries, religious and charitable organisations founded a variety of large hospitals which still exist today. It was not until the 20th century that the State significantly expanded its healthcare provision<sup>4</sup>. With the 1970 Health Act, responsibility for health services were removed from the local authority system and reorganised into eight regional health boards under the Department of Health<sup>5</sup>. In 2001, the number of health boards increased from eight to eleven. However, following the 2004 Health Act, these were abolished and the Health Service Executive (HSE) was established.

The establishment of the HSE marked a significant shift from a decentralised to a centralised, nationally governed health system<sup>6</sup>. According to the 2004 Health Act, the HSE 'shall manage and shall deliver, or arrange to be delivered on its behalf, health and personal social services'<sup>7</sup>. While it is the responsibility of the HSE to provide health services, Section 7.4 of the 2004 Health Act acknowledges that the state cannot provide all health services and therefore, will fund organisations to deliver these services on its behalf- Sections 38 and 39 of the Health Act 2004 provide for this. In 2017, 39 organisations received funding under Section 38 of the Act, while over 2,000 organisations, the majority of which were voluntary, received funding under Section 39<sup>8</sup>. Of particular interest for this study is the scale of reliance on the voluntary sector. For example, approximately 23 per cent of all HSE funding was allocated to voluntary organisations in 2017<sup>9</sup>.

### Governance

The governance structure for the HSE is outlined below in Figure 2.1. As mentioned above, the Health Act 2004 removed the system of localised accountability and made the HSE accountable directly to the Minister for Health. With the enactment of the HSE (Governance) Act 2013, a new directorate was established as the governing body of the HSE, under the leadership of the Director General. The directorate is accountable to the Minister for Health for the performance of its duties<sup>10</sup>.

**Figure 2.1 HSE Organisation Structure**



Source: HSE Code of Governance <sup>11</sup>

### Financing of Health Services

The Irish healthcare system is predominantly financed through taxation (73 per cent) with out-of-pocket payments contributing 12 per cent and private health insurance contributing 14 per cent to overall financing in 2017<sup>12</sup>. In 2018, Ireland's health expenditure was 7 per cent of GDP, which is below the OECD average of 8.8 per cent<sup>13</sup>. Due to the nature of the Irish economy, it has been argued that GDP may not be an appropriate measure of health spending. This is because a significant proportion of GDP is not available for national consumption due to the large profits exported from international companies which have their headquarters in Ireland<sup>14</sup>. For example, when measured by health spending per capita, Ireland - who spent 4,869 USD per capita in 2018 - is significantly above the OECD average of 3,992 USD.

### Resources

Over the past decade, the health service has consistently run over budget and has required supplementary funding<sup>15</sup>. While from 2010-2015 there were reduced annual budget allocations due to the financial crisis and austerity, from 2016 the annual allocation increased. However, despite this increase, the health sector continued to overspend, with supplementary funding ranging from €195m to around €645m<sup>16</sup>.

By May 2019, the health service had already run over its annual budget by €170m. In response, the HSE executive management team put recruitment controls in place on a short-term basis 'to ensure that the HSE is demonstrating that it is living within the available resources provided to it by Government'<sup>17</sup>. While employment in acute services has continued to increase, with 820 new positions this year<sup>18</sup>, healthcare posts in primary care services have reduced with over 160 fewer positions in July 2019 compared to January 2019<sup>19</sup>. This is despite current healthcare policy and future goals for reform (such as Sláintecare) that favours an expansion of primary care services.

In terms of hospital resources, compared to other OECD countries, Ireland has a low supply of hospital beds (3 per 1,000 population) and the highest rate of patient bed occupancy at 95 per cent<sup>20</sup>. In addition, while Ireland has a comparably high number of nurses at 12.2 per 1,000 population, it is below the OECD average in terms of doctors at 3.2 per 1,000 population<sup>21</sup>. These factors have contributed to record levels of overcrowding in Emergency Departments<sup>22</sup>, as well as significant waiting times for outpatient services<sup>23</sup>.

### Coverage

Eligibility for healthcare in Ireland is not universal and is based primarily on residency and means. Under the provisions of the Health Act 1970, those on low incomes and their families can apply for a medical card which provides free access to an extensive range of health services including General Practitioner (GP) services, and in-patient/out-patient hospital services<sup>24</sup>. In December 2017, 33 per cent of the population had a medical card<sup>25</sup>. Those on low incomes who do not qualify for a medical card can apply for a GP visit card, which provides holders with free access to their GP. In addition to those on low incomes, this card is also available to all children under the age of 6 (as outlined in Budget 2020 this will rise to all children under the age of 8 from September 2020) and everyone over the age of 70. As of December 2017, 10 per cent of the population had a GP visit card<sup>26</sup>.

For those without a medical card, the public health system is available to all residents in Ireland subject to fees. These fees include 100 euro for presenting at an emergency department without a referral letter from a GP and 80 euro per day for hospital care (up to a maximum charge of 800 euro in a rolling 12-month period). In terms of outpatient services, public patients can face significant waiting times. As of May 2019, 556,411 patients – more than 10 percent of Ireland's population – were waiting for an outpatient appointment to see a specialist, with 106,145 waiting more than 18 months<sup>27</sup>.

With substantially long waiting times for specialist appointments, and record levels of overcrowding in emergency departments<sup>28</sup>, it is not surprising that almost half of the Irish population (45 per cent) pay for private health insurance<sup>29</sup>. Private healthcare in Ireland is unique as much of the care for private patients is delivered in public hospitals<sup>30</sup>. As a result, the Irish hospital system has come to be seen widely as a two-tier system, as the financially better off gain faster access to healthcare services than those who cannot afford to pay for private sector care<sup>31</sup>.

With regards to primary care, Ireland is an outlier in Europe as it does not offer universal health coverage<sup>32</sup>. Most GPs in Ireland are private practitioners. However, the majority provide services on behalf of the Health Service Executive, for example – to people with medical cards and GP visit cards. For the majority of the population who do not have one of these cards, GP visits require out-of-pocket fees which are approximately 60 euro per visit. These out-of-pocket fees have been shown to deter necessary medical visits<sup>33</sup>.

As outlined above, there are significant inequalities within the Irish health system. Health coverage is not universal, and there is a considerable proportion of the population without either private health insurance or a medical card. In order to gain a deeper understanding of inequalities within the Irish health system, access to diagnostic services was researched and analysed for three case study conditions – autism spectrum disorder, lung cancer and brain tumours. The findings from this research, as well as prevalence rates for each of the conditions are presented below.

## Autism

Autism Spectrum Disorders (ASD or autism) are 'a group of neuro-developmental conditions characterised by impairments in social interaction and communication, as well as restricted, repetitive and stereotyped patterns of behaviour'<sup>34</sup>. It is a lifelong condition that impacts people to varying degrees. Prevalence rates for autism vary significantly due to a number of factors including changes in diagnostic criteria, different measures used and a growing awareness of autism. In Ireland, there is no specific autism register to determine prevalence. However, a recent report by the Department of Health – which compiled data from numerous sources – suggests an estimated prevalence rate of 1-1.5 per cent<sup>35</sup>.

Despite the high prevalence of autism, Ireland does not have a national autism strategy or specific autism policies that outline a clear pathway to diagnosis. Instead, all children who were born after 2002 and have a disability (or whose parents suspect them of having a disability) are entitled to an assessment of their needs under the Disability Act 2005. As part of this assessment, a service statement is received which lists the health services and supports that will be provided to the child. The assessment of needs should start within three months from when the completed application form is received from the HSE and should be completed within three months from the date on which the assessment commenced. However, contrary to this timeframe, there continues to be long wait times to receive an assessment of need. In addition, parents explained that once an assessment was secured, they also faced long waiting times to access the therapies listed on the child's service statement.

As a result of these issues, there have been calls to develop a national autism strategy which was set out in the Autism Spectrum Disorder Bill 2017. This Bill proposes to 'provide for the development and implementation of a cross-departmental multi-agency autism spectrum disorder strategy and to provide for related matters'<sup>36</sup>. However, the Bill is still waiting to progress through the Oireachtas (the Irish parliament) and has been before Dáil Éireann (the lower house) since July 2017.

Since the drafting of this Bill, the Minister for Health has established a cross-divisional working group to undertake a review of the Irish health services for individuals with autism, which was published in December 2018. This review found that there has been a lack of implementation regarding previous reviews and policies. In addition, it found that the pathways to health services for people with autism in Ireland are 'unclear' and 'difficult to navigate'<sup>37</sup>. This was also reported by participants interviewed as part of this study.

As well as being unclear and difficult to navigate, the assessment process is also inequitable. As one child psychiatrist explained:

*"So, the assessment of need process, the parent or a professional can refer the child to the assessment officer locally who then has to go about trying to find an assessment for the child to get a diagnosis. And that again is very heterogeneous because the early intervention teams are*



*usually tasked with providing the assessment, but they can have different amounts of resources depending on the county or the health area. So, the assessment officer may need to source the assessment privately for example which means that it's not always done in line with best practice. And then in other areas of the country there may be well resourced teams where that is a multidisciplinary assessment but the waiting times for that are excessively long and so as a consequence of that, many children are not getting diagnosed for a long time".*

The consultant child psychiatrist highlighted numerous inequities that can exist for children when trying to access a diagnosis of autism or an assessment of need. For example, some areas do not have the staff to make a multidisciplinary assessment. In addition, where wait times are very long, parents who have the means may choose to get their child assessed privately. In comparison, a child whose parents cannot afford a private assessment will have to wait. In some areas of the country, such as Cork, waiting times are over two years<sup>38</sup>.

### **Lung Cancer**

Lung cancer is one of the most common cancers in Ireland, with about 2,500 people diagnosed each year<sup>39</sup>. In many cases, the development of lung cancer is due to lifestyle choices. For example, smoking is the main cause of lung cancer and is responsible for nine out of every ten lung cancer cases. In Ireland, more people die of lung cancer than any other cancer<sup>40</sup>.

Ireland is currently pursuing its third national cancer strategy. Following recommendations made in the second cancer strategy, the National Cancer Control Programme (NCCP) was established to reorganise the way cancer care is delivered with the aim of improving cancer survival rates in Ireland. Under this programme, cancer services were centralised, and nine designated cancer centres were established. Patients are referred to these centres for cancer diagnosis and treatment by a GP. A major element of the NCCP is to ensure the 'promotion of early accurate diagnosis'<sup>41</sup>. As such, eight of the nine cancer centres have rapid access clinics for the diagnosis of lung cancer.

The NCCP uses Key Performance Indicators (KPIs) *"to assess services, to make comparisons between centres and identify areas for improvement as well as sharing good practice"*<sup>42</sup>. One such KPI is the percentage of patients who attend or are offered an appointment within 10 days of referral to a rapid access lung clinic. The target set by the NCCP is that 95 per cent of patients will receive an appointment within this time frame. In 2018, 88.2 per cent of patients had received an appointment within the target time frame<sup>43</sup>. Although the NCCP target was not met, there is research to suggest that rapid access clinics have significantly reduced the disparity in waiting times for diagnostic tests between public and private patients. For example, a report published by the Irish College of General Practice and the Irish Cancer Society found that the average difference in wait times for a chest x-ray between the public and private system is one day<sup>44</sup>. In addition, inequities present in other parts of the health system do not apply in the rapid access lung clinics. This was explained by a lung cancer consultant interviewed for this study:

*"I'd be quite proud of the fact that we don't have two waiting lists. If somebody books in for a bronchoscopy, which is a procedure that we do, on a list here who happens to have health insurance and the hospital books them in as a private patient, they're on the same waiting list, done on the same list as a public patient. There's no real preferential treatment of any sort".*

While rapid access clinics have helped to decrease the disparity in wait times between public and private patients, challenges for early diagnosis of lung cancer remain. For instance, a report published by the National Cancer Registry and Irish Cancer Society found that access to early diagnosis of cancer is less likely if you are from a deprived area or are over 65 years old. In addition, the prevalence of lung cancer in women is increasing, and more women in Ireland are now dying from lung cancer than from breast cancer<sup>45</sup>. The group most at risk are young disadvantaged women, who are significantly more likely to smoke.

### **Brain Tumour**

Brain tumours are considered a rare cancer. In Ireland, they rank 16 among the most common cancers, with a total of 390 new cases per year, and are responsible for 3 per cent of all cancer-related deaths<sup>46</sup>.

Like lung cancer, patients in Ireland are referred by their GP to a designated cancer centre for brain tumour diagnosis and treatment. However, there are no rapid access clinics for the detection and treatment of brain tumours. Pathways and timelines for brain tumour diagnosis depend on a number of factors including types of patient symptoms, where the patient first presents and GP knowledge. For example, some brain tumours can present acutely during a sudden severe event, which would bring the patient to hospital quite quickly. If this happens, the patient would be kept in hospital and then be scanned and referred to a Neurosurgical Centre. If they are kept in hospital, they must be accepted by the Neurosurgical Centre within one week, as this is a requirement of the Health Information and Quality Authority (HIQA). As such, this category of patient usually receives a diagnosis within one week.

In comparison, if someone has vague symptoms such as a headache, they may need to present to their GP a number of times before they are referred for a MRI scan. Wait times for the scan will differ depending on where the GP refers them to. As one neurosurgical nurse explained:

*"If you're waiting for an outpatient scan from a GP in the public service it could take longer than if they're sent privately to a private scanning facility. But some GPs would know that they would get faster access if they send the patient with a letter to an A&E. So, it depends on how the GP priorities that patient and where they send them to as to how quickly they would get access to a neurosurgeon or a neurosurgical centre."*

As outlined above, there is no clear pathway to diagnosis for brain tumour patients and the length of time spent waiting for a diagnosis can differ depending on a number of factors. For example, average wait times for a brain MRI through the public system, for which no rapid access clinic exists, is 126 days, while the average wait time through the private system is six days<sup>47</sup>. As such, access to diagnostic services can be much quicker for people who have the ability to pay for these services through the private healthcare system.

## **2.4 Germany**

### **The German Health System**

In 1883, Germany became the first country to establish a nationwide social health insurance system. More than 135 years later, the defining principles of solidarity and self-governance remain at the core of its health insurance system<sup>48</sup>. First, solidarity manifests itself both in the financing and the utilisation of health services: All insured individuals contribute a percentage of their income to statutory health insurance. In turn, individuals are entitled to access health services—irrespective of ability to pay,

socioeconomic background or geographical location. Since 2009, all citizens and permanent residents must have health insurance. Employees and other groups (e.g., pensioners or students) earning less than €57,600 (2017) and their non-earning dependents, have mandatory statutory health insurance (SHI). Individuals with a gross income above the threshold, self-employed and certain professional groups (e.g., civil servants) can purchase substitutive private health insurance (PHI)<sup>49</sup>.

Second, the German health system is characterised by self-governance. Decision-making powers are shared between the federal government, the federal states and civil society organisations. The former two traditionally delegate powers to membership-based (with mandatory participation), self-regulated organisations of payers and providers. As of 2017, 113 competing not-for-profit, self-governing, sickness funds provide statutory health insurance<sup>50</sup>.

### **Financing of Health Services**

Although there have only been modest increases in health expenditure since the early 2000s, health expenditure in Germany continues to be amongst the highest in Europe. Germany spent €3,996 per capita on health in 2015, 43 percent more than the average (€2,797). In fact, Germany spends a greater proportion of its GDP on health (11.2 percent) than any other country in the EU (average: 9.9 percent)<sup>51</sup>.

Health spending in Germany is mostly related to public expenditure. In 2015, 84.5 percent of total health expenditure was public (the highest share in the EU). Conversely, 12.5 percent of spending is out-of-pocket expenditure, which refers to charges or fees (co-payments, co-insurance, and or deductibles) that patients are required to pay. These direct payments include costs for the consultation with health professionals, medical procedures, medicines or laboratory tests. In terms of household consumption, out-of-pocket expenditure in Germany accounts for only 1.8 percent. Overall, the German health system therefore has high expenditure but low levels of private cost-sharing.

### **Resources**

In comparison to other European countries, Germany not only has high health expenditure, but also resources. With 813 beds per 100,000 population, it has the largest hospital inpatient sector in the EU (58 percent above the average). Further, the German health system has a high and growing number of physicians, with per population ratios and growth rates well above the EU average. For instance, since 2004, the number of full-time equivalent physicians in hospitals increased by 30 percent (from 125,000 to 163,000 in 2015). Nevertheless, given the high number of hospital beds, the physician to bed ratio is comparatively low and the nurse to bed ratio is one of the lowest in the EU<sup>52</sup>.

### **Coverage**

As discussed above, coverage of health services in Germany is nearly universal and health insurance mandatory. In 2015, approximately 88 percent of the population was covered by statutory health insurance, 10 percent by private health insurance and the remainder are covered under special schemes (e.g. soldiers). Despite the legal mandate to have health insurance, it has been estimated that about 0.1 percent of the population (approximately 79,000 people) did not have insurance in 2015. This is due to administrative obstacles or because individuals are unable to pay the premia for private health insurance or social security contribution (for example, low-income self-employed individuals). This issue affects particularly undocumented migrants who, in principle, have a right to health care, but who often cannot access services because of language barriers or for fear of legal consequences<sup>53</sup>.

Reflecting the high coverage and public health expenditure, only 0.5 percent of the German population self-report having unmet needs in medical care which is amongst the lowest in Europe. These unmet needs are not necessarily due to income, as is often the case in many European countries. Instead, unmet needs arise due to perceived discrimination, because of longer waiting times or not having private health insurance<sup>54</sup>. Further, some population groups in Germany have access only to a limited set of health benefits, such as asylum seekers, refugees and irregular migrants during the first 15 months of their stay in Germany. During this period, the legal right covers only acute or painful conditions, care related to pregnancy, health check-ups for children and vaccinations (although some federal states provide the normal benefits package, thereby causing regional variation).

## **Governance**

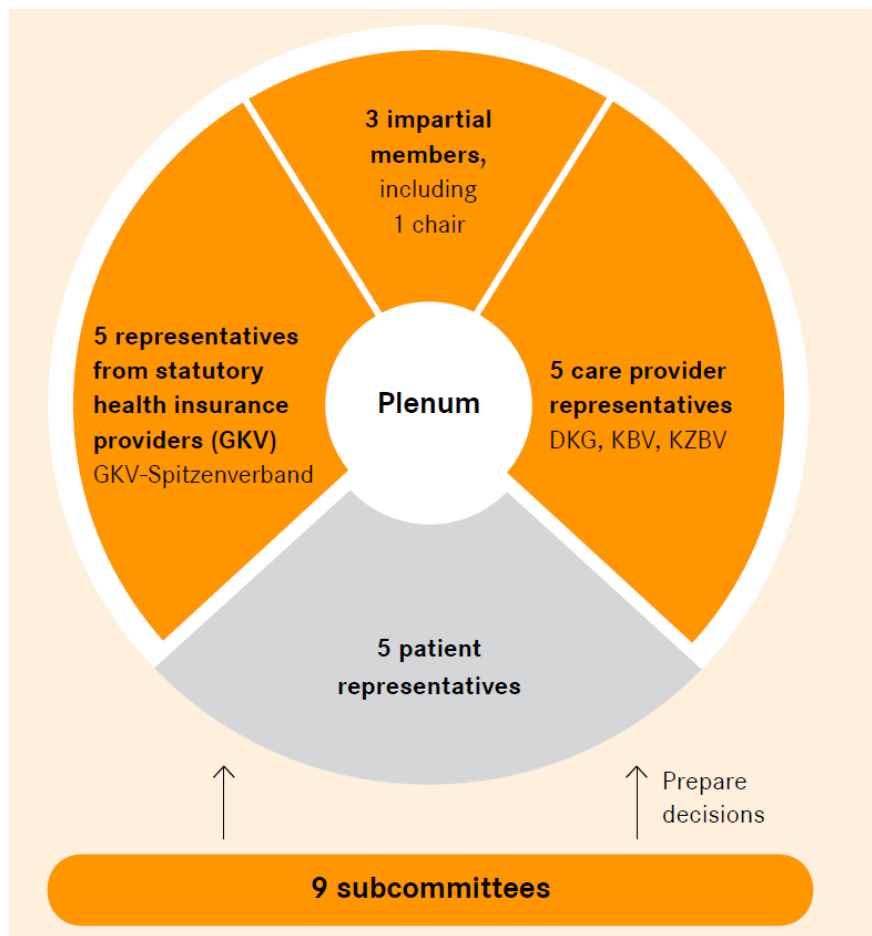
The Federal Ministry of Health focuses its activities predominantly on the drafting of bills, ordinances and administrative regulations. At its core lies the task of safeguarding and further developing the effectiveness of the statutory health insurance. For instance, the Ministry conducted a major health care reform to enhance the quality and efficiency of the health system in 2007 and strengthened patients' interests, while ensuring the stabilization of contribution rates. Moreover, the Federal Ministry of Health seeks to improve population health by means of prevention campaigns. In recent years, examples include the '3,000 Steps' (a campaign against a lack of exercise) or 'Life has Weight' (a campaign against eating disorders) initiatives. Taken together, the scope of operations by the Federal Ministry of Health cover the areas of health, prevention and long-term care.

While the Ministry of Health defines the legal framework, the regulatory details are specified in directives issued by the Federal Joint Committee (Gemainer Bundesausschuss, G-BA)—the highest decision-making body. In addition, the states supervise self-governing bodies at state level and are responsible for hospital planning and investments as well as medical education. In the discussion, the report focuses solely on the Federal Joint Committee as the highest decision-making body. The Federal Joint Committee is a self-governance institution which combines the interests of payers—health insurance funds—and providers—i.e., physicians, dentists and hospitals. The lawmakers have given the Committee the mandate (through the German Social Code, Book Five, SGB V) to regulate access to and the distribution of health services, benefits coverage and coordination of care. In addition, the Committee specifies measures for quality assurance and efficiency. It operates under the legal supervision of the Federal Ministry of Health and reports back to the Ministry with directives for review.

The resolution committee of the Federal Joint Committee (the plenum) comprises 13 members—as depicted in Figure 2.2: The plenum meets once or twice a month in a public session to discuss matters related to its mandate. Further, the plenum appoints subcommittees to prepare decisions and resolutions, including on pharmaceuticals, methods assessment, quality assurance or dental care<sup>55</sup>.

Leading nationwide advocacy groups that represent patient interests are entitled to participate in discussions and submit petitions, but not to vote. At present, the following patient and self-help organisations are entitled to appoint five patient representatives to the Committee<sup>56</sup>:

- The German Council of People with Disabilities
- The Federal Syndicate of Patient Interest Groups
- The German Syndicate of Self-Help Groups
- The Federation of German Consumer Organisations

**Figure 2.2: The Federal Joint Committee**

Abbreviations: GKV-Spitzenverband: National Association of Statutory Health Insurance Funds; DKG: German Hospital Federation; KBV: National Association of Statutory Health Insurance Physicians; KZBV: National Association of Statutory Health Insurance Dentists

Source: Gemeiner Bundesausschuss<sup>57</sup>

While the focus on the (governance of) health system is important, all case study conditions are interdisciplinary and extend beyond these aspects. For instance, medical staff (specifically psychiatrists) diagnose autism. Yet therapeutic institutions receive payments from the 'Eingliederungshilfe', a section of the Social Assistance Act which regulates the services to which individuals with disabilities are entitled. These services include special education or integration to the labour market. Thus, other economic and social policies—including education and labour market policies—are also relevant for individuals with autism and civil society organisations speaking on their behalf. These aspects are beyond the remit of this report and the impact of social and economic policies on health inequalities are discussed elsewhere (For example, see Forster, Kentikelenis, and Bamba<sup>58</sup>).

Similar to autism, the diagnosis and treatment of cancer also involves multiple actors. According to several interviewees, the German health system is relatively well-equipped to deal with the direct medical consequences of cancer. However, this is not necessarily true for indirect consequences of a diagnosis and treatment, such as psychological repercussions. While this has been recognised and psycho-oncologists are trained, demand currently far exceeds supply for these services.

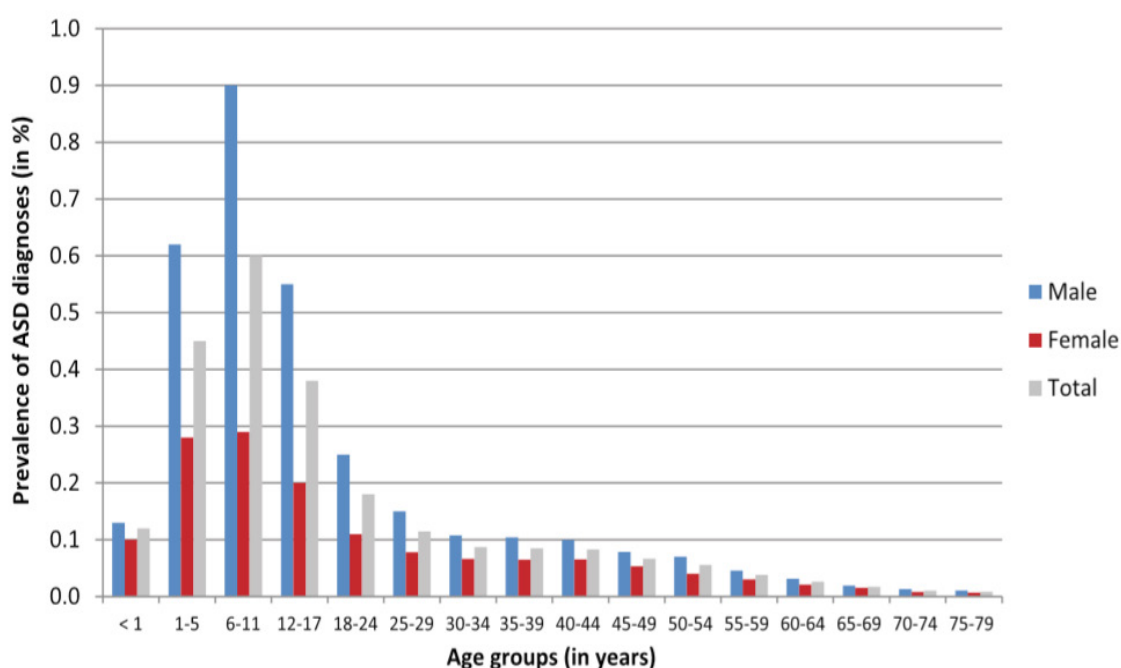
As outlined above, the financing and organisation of the German health system makes it relatively equitable in an international context. Nonetheless, inequalities in health exist, for example, due to the

geographic distribution of health services providers. In addition, the complex nature of the health and social care system suggests that individuals with higher health literacy may have favourable access to health services. This also extends to the governance of the health system, where experienced actors with superior knowledge of the governance structures—such as representatives from industry or health insurance providers—are at a relative advantage. To better understand how health inequalities arise in the German system and how they can be reduced, we now turn to the three case study conditions, their prevalence rates and diagnostic processes in more detail.

### Autism

Germany has no centrally administered data on the prevalence of autism spectrum disorder (ASD). However, academics examined administrative outpatient data from a nationwide health insurance fund over the period of 2006 to 2012 to compute the prevalence of ASD diagnoses for each year, disaggregated by age and sex<sup>59</sup>. Figure 2.3 depicts the prevalence of ASD diagnoses in 2012. In young children, the prevalence peaks in 6- to 11-year-olds (total prevalence: 0.60 percent, boys: 0.90 percent, girls: 0.29 percent). Over subsequent age groups, ASD diagnoses decrease and fall under 0.10 percent in individuals aged 30 and above.

**Figure 2.3: Prevalence of ASD Diagnoses in 2012**



Note: Prevalence of ASD diagnoses in 2012 based on administrative data (in percent).

Source: Bachmann et al. (2018)<sup>60</sup>

In terms of time trends, only data for children, adolescents and young adults (0-24 years) are available; in all these age groups, the administrative data records a marked increase in the prevalence of ASD diagnoses between 2006 and 2012. This increase is not yet fully understood because it could reflect

both increased awareness among the public and better access to mental health services or a real increase in the incidence of ASD<sup>61</sup>. Further, since there are no standards for the diagnosis of ASD in Germany, the prevalence of ASD has to be inferred on the basis of selected health services that patients use. Of course, collecting data on the prevalence and incidence of ASD is important from an academic and health policy-perspective, but the more pressing issue for patients is whether they can obtain a timely diagnosis.

In 2016, the German Society for Child and Youth Psychiatry, Psychosomatic Medicine and Psychotherapy (DGKJP) and the German Association for Psychiatry, Psychotherapy and Psychosomatics (DGPPN) published the S3 Guidelines for diagnosis of ASD. Drawing on research and directives from other countries, such as the UK, this guideline specifies recommendations on how psychiatrists should diagnose autism. It describes different survey and screening methods, tailored to the diverse experiences of people with autism depending on their age.

Yet, inequalities in diagnosis of autism continue to exist and interviewees identified two key causes. First, since autism and its diagnosis involve actors from the realm of both health and social policy, parents and relatives of autistic people find it difficult to navigate the regulatory landscape. For children, early diagnosis of ASD is key and in many cases the first point of contact for parents of children with mental health concerns are paediatricians or general practitioners. These are—at times—ill-suited to deal with the question at hand. This is reflected in the low satisfaction with the diagnostic process. According to a recent study, only 38.5 percent of parents are satisfied with the diagnostic process. On average, parents visited 3.4 different health professionals until their children received a definite ASD diagnosis<sup>62</sup>. As a result, individuals with higher education or a denser network to medical staff may obtain a timelier diagnosis than others. For instance, the complexity of the process is particularly concerning for migrant populations who do not speak German.

Second, even if prospective patients are familiar with the diagnostic process, they need to access qualified medical staff. The diagnosis can only be performed by psychiatrists, but few psychiatrists actually have the educational background and expertise to do so. Due to a mismatch of demand and supply for the profession, diagnosis can involve many different practitioners and be time-consuming. Further, the excess demand leads to long waiting times—members of self-help groups reported to wait up to two years.

### **Lung Cancer**

In contrast to autism, the prevalence of cancer is better documented. Between 2004 and 2014, new cancer patients increased by approximately 8 percent and almost doubled since 1970. This trend is primarily due to the demographic change of the German population. Every year, approximately 480,000 individuals (almost 6 percent of German's population) are diagnosed with cancer and this number is expected to increase by at least 20 percent until 2030<sup>63</sup>. Lung cancer is associated with high rates of mortality and accounted for 5 percent of all deaths in 2014—second only to cardiovascular diseases<sup>64</sup>.

At the start of the diagnosis of lung cancer, a doctor and patient discuss any symptoms the patient may be experiencing such as breathlessness or a persistent cough. Subsequently to this anamnesis, further analyses may be conducted. This ranges from blood tests to rule out other possible causes of the symptoms to a chest x-ray. In addition, a computerised tomography (CT) scan can be ordered and if it shows that there may be cancer in the central part of the chest, the individual will have a bronchoscopy.



This allows a doctor or nurse to remove a small sample of cells from inside the lungs. The results of the bronchoscopy, or similar procedures, enable the doctor to evaluate the stage of the cancer and determine the appropriate treatment.

Interviewees did not perceive any inequalities in access to these diagnostics since the procedures are covered by health insurance in Germany. Nonetheless, cancer centres cluster in big cities or university towns and individuals from sparsely populated areas in Germany may not find qualified doctors without considerable amount of travel. In addition, any diagnosis of lung cancer has severe ramifications for the daily life of an individual and their relatives. Thus, the network of friends and family differentially conditions the experience of a diagnosis.

### **Brain Tumours**

In contrast to lung cancer, brain tumours are less common. In Germany, around 2 percent of all cancer diagnoses relate to brain tumours: in 2014, approximately 3,160 women and 3,900 men were diagnosed<sup>65</sup>.

As with lung cancer, a doctor (general practitioner or neurologist) and patient initially discuss any symptoms the patient may be experiencing. To identify and locate a potential brain tumour, doctors perform a magnetic resonance imaging (MRI) scan and potentially a CT scan. Since these tests cannot unambiguously determine if there is cancer, neurosurgeons may carry out a biopsy—an operation to extract some sample tissue—to establish the type of tumour and the most effective treatment for the patient.

Interviewees were less concerned with inequalities in access to these diagnostics by socio-economic background. However, like lung cancer, the geographic distribution of cancer centres was raised as an issue. As one leader of a self-help group put it:

*"I don't think that inequalities are such a big problem. The system in Germany works quite well, ... staff in cancer centres know what they do, but these centres are distributed unevenly across Germany. The situation in Berlin ... with several hospitals ... is very good, but this isn't the case everywhere".*

## **2.5 Spain**

### **The Spanish Health System**

The universality of the Spanish health system dates back to 1986 when the General Health Law was approved. Subsequent reforms during the 2000s culminated in the Public Health Law in 2011 – which stated that all Spanish and migrant populations living in Spain were entitled to the right to health – and therefore, were eligible to health services free of charge. Until 2012, health coverage in Spain was almost universal (99.5%) and guaranteed a comprehensive package of benefits to all its citizens<sup>66</sup>.

However, in 2012, the Spanish Government enacted the Royal Decree-law 16/2012, which changed the basis for entitlement, linking the right to health to the legal and working status of the individual. The reforms were justified as a response to the financial crisis that was having devastating effects on the Spanish economy. However, there was controversy on the introduction of such measures, particularly when public health expenditure at the time was low at 7.0 per cent of GDP compared to the European Union average of 7.6 per cent<sup>67</sup>.



Since the implementation of the Royal Decree, it is estimated that 873,000 non-residents have lost their entitlement to health services<sup>68</sup>. However, this figure has been contested and some argue that it is much lower as a large number of non-residents migrated to other countries or went back to their home countries when the financial crisis hit Spain. These measures together with further restrictions and increased co-payments for Spanish citizens resulted in popular discontent and social movements that organised themselves to defend the public health system. In addition, some autonomous regions (e.g. Valencia, Cataluña, Andalucía) contested these measures arguing they could result in a public health threat and continued providing services to undocumented migrants and refused to introduce co-payments.

In June 2018, a new government was elected in Spain and announced their willingness to reverse the restrictions limiting universal protection for all its citizens including undocumented migrants, curtailing some of the co-payments and providing additional services. By July, the government had signed a new Royal Decree 7/2018 granting undocumented migrants the right to health protection and health care under the same conditions as people with Spanish nationality<sup>69</sup>.

### **Financing of Health Services**

In Spain, general taxes are the main source of public funding, with Autonomous Communities managing most of the health resources. In 2015, public expenditure represented 71.1 per cent of the total health expenditure, while private expenditure represented 28.9 per cent<sup>70</sup>. Out-of-pocket payments increased throughout the 2009-2015 period and reached 23.9 per cent of total health expenditure in 2015. Both private expenditure and out-of-pocket payments are higher than the EU average by 4 and 7 percentage points respectively<sup>71</sup>. Austerity measures introduced in 2009 had an impact on the funding of the Spanish National Health System. Up until 2009, health expenditure in Spain had followed an upward trend. However, that year the trend reversed, and expenditure decreased each year until 2016<sup>72</sup>.

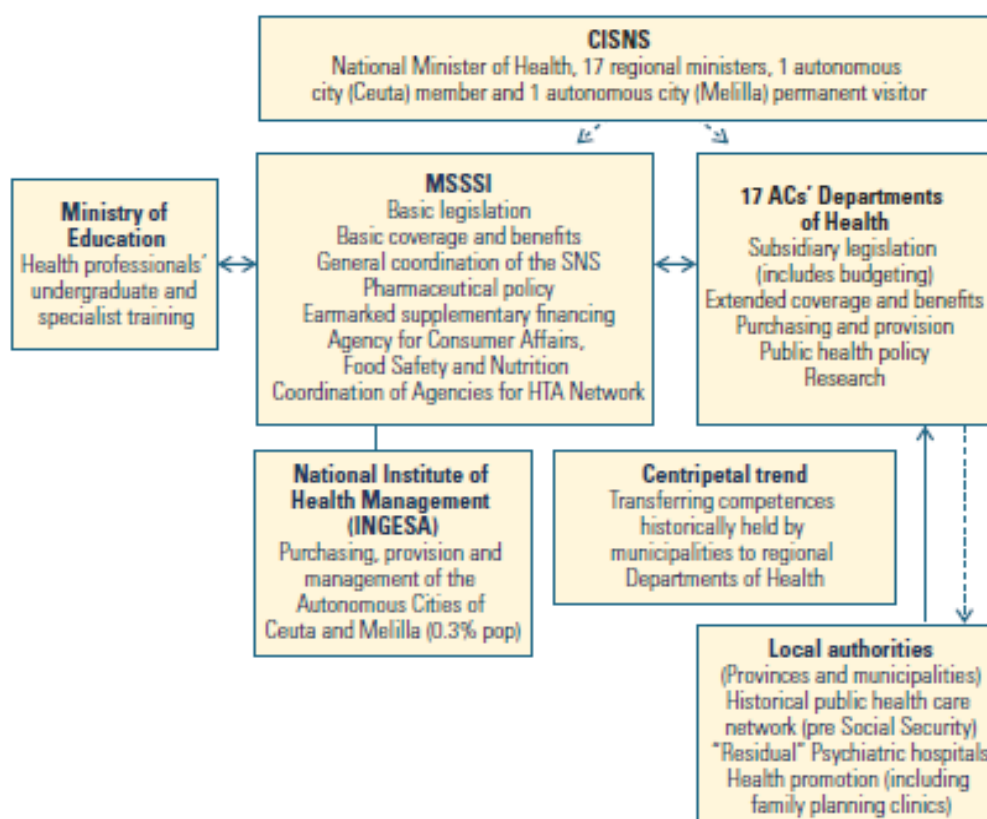
### **Resources**

The austerity policies in public expenditure that were introduced in 2010 also affected the resources available in the Spanish National Health System (NHS)<sup>73</sup>. Austerity measures resulted in 5 per cent salary reductions for NHS personnel, along with redundancies and a staff recruitment freeze<sup>74</sup>. During 2012 and 2013 staff numbers and salaries were further reduced and working hours for existing staff were increased<sup>75</sup>. In 2015, the number of hospital beds in Spain was 298 beds per 100,000 inhabitants, below the EU average of 340. The rate of doctors per 100,000 population in 2015 was 380, above the EU average of 350; and 534 nurses per 100,000, below the EU average of 864<sup>76</sup>.

### **Governance**

The national health ministry is responsible for basic legislation and general coordination and for the equitable functioning of the system, pharmaceutical legislation, border health issues and international health relations. All other issues are devolved to the 17 regions, which administer 90% of public healthcare funding<sup>77</sup>. Therefore, regional health administrations are responsible for regional health legislation, health insurance, health services planning, health services management and provision as well as public health. Local authorities are responsible for sanitation and collaborate with their respective Autonomous Communities in the provision of health services and managing public health and community services.

**Figure 2.4 Overview of the general statutory system**



Source: Spain, Health System in Transition 2018<sup>78</sup>.

As described above, Spain experienced a major transformation in its health system as a result of the financial crisis and austerity measures. Since 2012, Spain introduced the Royal Decree-law 16/2012, which changed the basis for entitlement, linking it to the working status of the individual. In addition, the introduction of co-payments and the cuts provided to health services might have increased health inequalities. Furthermore, the fact that not all Autonomous Communities followed the same approach, could have resulted in further health inequalities due to the diverse regional distribution of health service providers. In order to better understand health inequalities within the Spanish health system, we now discuss the three case study conditions, autism spectrum disorder, lung cancer and brain tumours. The findings from this research, as well as prevalence rates and diagnostic processes for each of the conditions are presented below.

### Autism

Spain does not have a central data registry on the prevalence of autism. However, the Spanish Strategy on Autism provides an estimate, stating that there may be more than 450,000 people living with autism in Spain (approximately 1 percent of Spain's population), although acknowledging that not all might be correctly identified and diagnosed<sup>79</sup>. Few studies have been conducted to estimate the prevalence of autism in Spain<sup>80</sup>. Those that are available have adopted different methodologies to assess the prevalence, provide variability on the prevalence results and most are outdated. The highest rate of case identification among children has been reported in Tarragona (belonging to the Autonomous Community of Cataluña) with a 15.5/1000 rate and the lowest rate has been identified in Cádiz (belonging to the Autonomous community of Andalucía) with a 0.2/1000 rate<sup>81</sup>. Other studies

include a screening study carried out in the Canary Islands with a sample of 1,796 children between 18 and 36 months, where the authors identified a prevalence rate of 6.1/1000<sup>82</sup>. In addition, there is a study by Morales-Hidalgo et al. in 2018 who worked with a sample of 2,765 schoolchildren in Tarragona<sup>83</sup>. They analysed two cohorts (children aged 4-5 and 10-11 years) in two phases (screening and diagnostic confirmation) and identified the highest rate so far in Spain, with figures similar to those most recently published internationally— 15.5/1000 in preschools and 10/1000 in schoolchildren<sup>84</sup>.

The Spanish Strategy for Autism approved by the Spanish Parliament in 2015, where civil society organizations participated, describes the key strategies that the Spanish Government will develop to cater for the needs of children and adults with autism. The main objectives consist of producing protocols in various areas including health, culture, education and employment. The strategy lines of action include promoting access to services, research, training, detection and diagnosis, early intervention, comprehensive intervention, health and health care, education, independent living, social inclusion and citizen participation, justice and empowerment of rights and support for families and employment<sup>85</sup>.

Within the health system, Spain has adopted internationally agreed screening protocols aimed at primary health care professionals (i.e., American Academy of Pediatrics, 2008, the M-CHAT questionnaire) for the detection of Autism in children at follow-up visits at 18 and 24 months. These protocols propose the application of a simple and brief questionnaire addressed to families to detect possible warning signs of autism and determine the need for referral of the child for later evaluation and specialised diagnosis<sup>86</sup>. In order to improve early detection, the Spanish Strategy for Autism establishes the need to provide screening training to primary health care teams<sup>87</sup>. In Spain, some Autonomous Communities have included the diagnosis of autism within their general healthcare programmes, others have developed specific detection programmes, while in other regions the diagnosis of autism is carried out within the Healthy Child Control Program, which aims to identify the risk of developmental disorders. As described by the participants in our study, services for the diagnosis of autism vary across the different Spanish Autonomous Communities with some regions having more dedicated and integrated programs than others.

Overall, participants reported difficulty navigating the health system when accessing diagnostic services for autism. For example, a mother mentioned that she considered herself lucky as her son had been diagnosed with Asperger's when he was 4 years old while other families have been diagnosed at 18, 17 or 20 years. The participant attributed this occurrence to the fact that she worked in the field of mental health "and knew how to move" within the system.

Geographical inequalities were also reported in relation to access to diagnostic services for autism. For example, the same participant mentioned that the tests to diagnose autism had not been available in all regions at the same time. In addition, while in some places (for example, Madrid) examples of coordinated autism care between professionals and families were provided, in other areas the lack of coordination and the lack of multidisciplinary teams working together were described with concern. Difficulty accessing public services was also reported by participants. They specifically expressed obstacles in accessing appropriate follow-up and continuous care:

*"We always fight and say that our children, our daughters, our brothers need continuous therapy and that the system does not have the resources to do therapy. It has resources to see that person with a bit of luck, once a month, this is very lucky".*

Furthermore, they suggested that diagnosis for autism was much faster when accessing private services compared to public services and outlined that the proliferation of private services within the field of autism was considered a reason for increased health inequities.

## Lung Cancer

In contrast to the lack of available data on the prevalence of autism, cancer data is better documented in Spain. The most recent prevalence, incidence and mortality data for cancer is available at REDECAN, a joint data set produced by the Spanish network of cancer registries. REDECAN is a compilation of 14 cancer registries endorsed by the Ministry of Health, Social Services and Equality (MSSI)<sup>88</sup>. In Spain, cancer is the second cause of death after cardiovascular diseases, although in men it has been the leading cause of death since 2000. In 2016, three out of every 10 deaths in men and two in 10 in women were due to cancer<sup>89</sup>. The total number of cases estimated for 2019 is 277,234 of which 161,064 are in men and 116,170 in women. The most common is cancer of the colon and rectum with 44,937 new cases, followed by prostate cancer with 34,394, breast cancer with 32,536 and lung cancer with 29,503 new cases. Brain cancer is less common with 4,401 new cases in 2019<sup>90</sup>.

Spain also developed a Cancer Strategy within the National Health System in 2010, which included screening for breast, colon, cervix and prostate cancer. However, no screening tests were suggested for early diagnosis of lung cancer. In Spain, the Spanish Society of Medical Oncology (SEOM) through the contributions of National Research Cooperatives and with the participation of members of other Scientific Societies publishes each year the Clinical Guidelines that incorporate the latest advances in the diagnosis and treatment of cancer.

Most participants reported and emphasised geographical inequalities in the diagnosis and treatment of lung cancer. Geographical inequalities were identified between autonomous communities. For example, it was suggested that specialised treatment is of better quality in cities such as Madrid or Barcelona than in the rest of Spain. Health care professionals also mentioned that health inequalities exist within Autonomous Communities. It was suggested that access to health and specialised treatment varies between the largest cities, smaller towns and rural areas within the same Autonomous Community.

Participants also reported that waiting times were a challenge for all patients' needing services. While rapid diagnostic units for lung cancer, which have virtually no waiting lists, have been established, these are not available in all autonomous communities. As such, long wait times persist in some areas, which can pose a serious problem for patients. As one consultant explained:

*"So, if my patient is going to have a PET [positron emission tomography] done in six weeks and then I have to do a bronchoscopy, it will take two or three months to diagnose lung cancer. The median survival of stage four lung cancer is six months".*

## Brain Tumours

Incidence and mortality data on brain tumours is not available by Autonomous Communities in the aforementioned database, although some studies have attempted to fill this gap. For example, Etxeberria et al in 2018 analysed two regions in the north of Spain: Navarre and Basque Country. From 1990 to 2008, 4,495 cases of malignant brain tumours were reported (55.24% males and 44.76% females) and 3,201 deaths (55.20% males and 44.80% females), giving an overall crude rate of 8.90 cases per 100,000 inhabitants and an overall crude mortality rate of 6.34 cases per 100,000 inhabitants<sup>91</sup>. In addition,

Ugarte et al. in 2015, conducted an analysis on the evolution of relative mortality risk in young people under 20 years of age with brain cancer between 1986 and 2010 in the different regions of Spain. They emphasized the contrast between a high risk of relative morbidity in Navarra compared to a low risk of relative mortality in Madrid. Regarding the differences in mortality over time and between regions, the authors concluded that it may be caused by the increase in survival rates, the differences in treatment or the availability of diagnostic tools. The authors suggest that the increase in relative risks observed in the 1990s was probably due to improved diagnostics with magnetic resonance imaging techniques and computerized axial tomography. Overall, the results from the study suggest geographical health inequalities in the treatment of brain cancer across Spain<sup>92</sup>.

This was echoed by the participants interviewed for this report. Like lung cancer, participants outlined that geographical inequalities in access to diagnostic services and treatment for brain tumours existed both between and within Autonomous Communities. For example, there was a clear idea among participants of where treatment was considered better quality. Experts recognised that the very best treatment was often provided in bigger cities such as Barcelona and Madrid. In addition, it was reported that some hospitals do not have the resources to provide treatment, so patients have to travel to different centres.

Emphasising the geographical inequalities, health care professionals reported that patients do not receive the same medical treatment in certain regions due to the lack of specialists and attributed this to a "postcode lottery". In addition, health care professionals noted that there are differences in the level of expertise of professionals in different hospitals. For instance, whereas some hospitals have a team of professionals who are exclusively dedicated to brain tumours, in other hospitals the surgery teams have to assume a wider spectrum of interventions. As highlighted by a brain tumour specialist in one of the main hospitals:

*"A surgeon in a provincial hospital will operate on many backs, because there is a lot of demand in the population for back operations and suddenly a glioblastoma will arrive every six months. [In comparison] we, to give you an idea, have a surgeon who only operates brain tumours..., that maybe operates sixty glioblastomas a year".*

## 2.6 Conclusion

This chapter provided an overview of the health systems in Ireland, Germany and Spain. Each of these three European countries has a contrasting type of health system, which is significant in relation to healthcare coverage and access. Eligibility to healthcare in Ireland is not universal and is based primarily on residency and means. In contrast, Spain has a National Health Service and German healthcare operates through a Social Insurance System which both provide almost universal coverage. In addition, this chapter examined health inequalities within each of the health systems. This was addressed through a case study approach, focusing on access to diagnosis for three conditions: autism spectrum disorder, lung cancer and brain tumours.

In Germany and Spain, where healthcare coverage is almost universal, the main inequalities in relation to access to diagnosis for lung cancer and brain tumours were geographical, as cancer centres and specialists tend to be located in large cities. In comparison, in Ireland, inequalities in access to diagnostic services are very much rooted in socio-economic factors. For example, access to brain tumour diagnostic services is much quicker for those who can afford to use the private sector. In terms

of lung cancer, rapid access clinics have helped to decrease the disparity in wait times between public and private patients. However, challenges for early diagnosis remain, especially for those living in deprived areas.

While the type of health system appears to influence the inequalities in access to cancer diagnoses, this was not the case for autism. The experiences of accessing diagnostic services for autism were similar across the three countries. For example, participants in all countries found it difficult to navigate the assessment process and reported wait times of up to 2 years. In addition, they outlined regional inequalities, and explained that faster diagnoses could be accessed through private services.

The findings from this chapter suggest that health systems with universal coverage reduce inequalities based on socio-economic grounds for certain conditions, such as cancer. For complex conditions such as autism, which requires coordination between health and social services, type of health system was not as significant a factor in reducing inequalities. Instead, the ability to pay to access services privately and to navigate through complex health systems contributes significantly to socio-economic inequalities.

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# 3. The Role of Civil Society in Reducing Health Inequalities

# 3. The Role of Civil Society in Reducing Health Inequalities

## *3.1 Chapter Summary*

- This chapter outlines the role that CSOs have in reducing health inequalities.
- It identifies two pathways - directly and indirectly - through which CSOs can reduce health inequalities for those affected by the case study conditions.
- CSOs reduce health inequalities by providing services directly to patients and their families.
- CSOs also reduce health inequalities indirectly by influencing policy.
- With regards to the direct pathway, the chapter highlights that CSOs in all three countries have a significant impact in terms of reducing health inequalities for the case study conditions.
- Common services provided by CSOs across the three countries include: information provision, advocacy work, support groups, diagnostic services and therapies, residential care and respite and transport to healthcare appointments.
- In terms of the indirect pathway, the size of the organisation tended to reflect whether or not CSOs had an impact on policy.
- While umbrella organisations and medical societies had a significant impact on policy, smaller organisations across the three countries did not.
- The chapter finds Germany to have the most significant impact on policy due to the formal structures within the German health system that facilitate communication with policymakers and engagement with the legislative process.

## *3.2 Chapter Outline*

Civil Society Organisations (CSOs) tend to establish in response to a need for services which are not adequately provided by the state. As such, the role of CSOs in this report serves as an indicator of where the state is failing in relation to healthcare access. Drawing on examples from the three case study conditions, this chapter discusses the role that CSOs have in reducing health inequalities. It highlights the number of organisations for each condition, how they are funded, the services they provide, the strategies used to influence change as well as the barriers they face. The chapter concludes by comparing the role of CSOs across the three countries and outlining the impact that they have on patients and their families.

## *3.3 Ireland*

### **Overview of Civil Society Organisations**



Civil society organisations in Ireland operate at local, regional and national levels and vary significantly in their objectives and activities. For analysis purposes, a typology of Irish CSOs was developed and included below.

**Figure 3.1: A Typology of Irish Civil Society Organisations**

<b>Umbrella</b>	<b>National</b>	<b>Therapeutic</b>	<b>Regional / Local</b>	<b>Characteristics</b>
<ul style="list-style-type: none"> <li>• Representative bodies for national organisations</li> <li>• Good communication channels with the HSE and Department of Health</li> </ul>	<ul style="list-style-type: none"> <li>• Represents patients and families of specific conditions at national level</li> <li>• Are members of umbrella organisations</li> </ul>	<ul style="list-style-type: none"> <li>• Main purpose is to provide health and residential services</li> </ul>	<ul style="list-style-type: none"> <li>• Establish around specific service needs</li> <li>• Parent-led organisations</li> <li>• Not registered charity</li> <li>• Can exist for a short period until goals are met</li> </ul>	
<ul style="list-style-type: none"> <li>• HSE</li> <li>• Other State funding</li> <li>• Affiliation and membership fees</li> </ul>	<ul style="list-style-type: none"> <li>• HSE</li> <li>• Other State funding</li> <li>• Fundraising</li> <li>• Donations</li> </ul>	<ul style="list-style-type: none"> <li>• HSE</li> <li>• Other State funding</li> <li>• Donations</li> </ul>	<ul style="list-style-type: none"> <li>• Self funded – mainly by parents and other individual donors</li> </ul>	<b>Funding</b>
<ul style="list-style-type: none"> <li>• Health policy</li> <li>• Lobbying</li> <li>• Advocacy</li> <li>• Members of HSE committees</li> <li>• Host consultations for member organisations</li> <li>• Training</li> <li>• Information Provision</li> </ul>	<ul style="list-style-type: none"> <li>• Information provision</li> <li>• Training</li> <li>• Support groups</li> <li>• Advocacy</li> <li>• Lobbying</li> <li>• Health policy</li> </ul>	<ul style="list-style-type: none"> <li>• Residential care</li> <li>• Respite</li> <li>• Therapies</li> </ul>	<ul style="list-style-type: none"> <li>• Lobbying</li> <li>• Advocacy</li> </ul>	<b>Services</b>

Note: The typology is derived for analytical purposes only. In practice, civil society organisations may operate various roles, with significant overlap between the classifications outlined above.

Source: Author, based on information online and interviews

In Ireland, the Charities Regulator holds information on all registered charities. In order to determine how many CSOs there are for each of the case study conditions, the Charities Regulator website was searched using the following key terms: 'autism', 'lung cancer' and 'brain tumour'. Out of the three specific conditions, 'autism' returned the highest number of registered charities at 38. In addition to these, many local CSOs are not registered charities and therefore, are not included on the Charities Regulator website. In contrast to this high volume, 'brain tumour' returned just 2 registered charities on the Charities Regulator website, while there were no results for the 'lung cancer' search. However, it is worth highlighting that information and support services for the two cancers are available from national cancer organisations and local cancer support groups. For example, when searching more broadly, the term 'cancer' returned 71 registered cancer charities.

### Establishment of CSOs

The majority of the organisations interviewed were originally established by parents or family members. The interviewees explained that they established the organisations due to challenges they faced such as accessing appropriate information or services after a diagnosis. For the majority of these organisations, the parents or family members who originally established the organisations are still involved as board members. In terms of the local autism groups interviewed, these were all established and run by mothers of children with autism. One exception to this trend of parent and family-led organisations is some of the cancer charities, which were originally established by medical practitioners.

## Funding of CSOs

As outlined above, CSOs have an important role in healthcare provision due to the historical development of healthcare in Ireland. In August 2017, the Minister for Health established an Independent Review Group to examine the role of voluntary organisations in the provision of health and personal social services. This report was published in February 2019 and found that for the year 2017, the state paid voluntary organisations just under a quarter of the HSE budget.

As outlined in the report, the volume of funding provided by the State to CSOs demonstrates a significant mutual reliance – by the State on voluntary organisations for the provision of services and by voluntary organisations on the State for funding. However, the relationship between the two – the voluntary sector and the State, represented by the HSE as the funding agency – was found to be strained. In addition, the report outlined that the demands on CSOs for requests for information in various formats from multiple units in the HSE imposed a huge burden on smaller organisations<sup>93</sup>.

In terms of the current research, the CSOs that are funded by the HSE reported similar issues. As outlined in Figure 3.1, the HSE is the main funder for Umbrella organisations, National organisations and Therapeutic organisations. While large organisations outlined that they are comfortable challenging the HSE in their advocacy role, smaller CSOs noted that they are reluctant to be critical of state services due to their reliance on the HSE for funding. In addition to HSE funding, these organisations also rely on other state funding, donations, fundraising, and in some cases, membership and affiliation fees. In contrast, local and regional CSOs tended to be self-funded.

## Services provided by CSOs

Civil society organisations in Ireland provide a broad range of services. For the organisations interviewed, the services provided included: information provision, training, support groups, residential care and respite, hospice services, transport to hospital appointments and therapies, and advocacy work. The most common service provided by organisations was information provision. Many of the autism organisations outlined that when parents first receive a diagnosis for their child they do not know where to go to access services. Other parents contact the organisation as they suspect that their child has autism and are unsure of the pathways to assessment. One autism organisation outlined that while they can inform parents of the different pathways, they are frustrated that they cannot tell them how long this process will take:

*"So, we would get a lot of parents who notice something wrong and will say what will we do, and we will explain what they need to do, they can go publicly or privately, and we will always tell them they have the two options. And then you will hear from parents that they're waiting, at each stage of the referral process, they're waiting, and they don't know how long they're going to wait, and you can't tell them".*

Due to long wait times for both the assessment of need and therapies for children with autism, a number of organisations interviewed also did case advocacy work, where they helped the parents of the child with autism either submit a complaint through the HSE where the child was not receiving services, or recommend them for court action if they were waiting for an assessment longer than the time specified in the Disability Act 2005.

In addition to the services outlined above, all the organisations interviewed also engaged in lobbying and had particular strategies they used to try to influence change. These included making written

submissions to government, presenting to Oireachtas Committees, awareness campaigns, conducting research and disseminating findings to highlight a need for services, as well as meeting with government Ministers and local TDs. The organisations interviewed reported various levels of success influencing change. For example, a staff member working for an umbrella organisation explained that meeting face-to-face with people on HSE committees allowed them to get their recommendations across. He explained:

*"We're on various committees in the HSE and we'll raise it there, we'll raise it at the committees. And you know, you're face-to-face with people, we'd be quite strong with it".*

However, for most organisations this was not the case, with some CSOs reporting significant barriers to influencing change.

### **Barriers to influencing change**

#### Lack of representation or engagement with other organisations

Regional and small national organisations outlined that a lack of representation by, or engagement with, larger national and umbrella organisations was a barrier to influencing change. In terms of autism, one group of parents felt that larger organisations were not representing all children on the autism spectrum equally, as autism campaigns tended to favour those with less complex needs. This lack of representation was also felt by those working in the field of brain tumours, who maintained that: *"There's no engagement or no willingness to promote it. You're kind of like the forgotten cancer."*

#### Funding and independence

As outline above, some of the organisations reported that funding was a barrier to influencing change. This issue was also raised at the roundtable event, where the group of civil society organisations explained that they compete with each other for state funding and as such, increasingly provide services that benefit the government or HSE in order to secure funding. This was outlined as a co-option model, with some organisations noting that it waters down critique of state services. However, it is worth highlighting that larger established organisations that are funded by the HSE explicitly stated that they feel comfortable criticising it.

#### Political will

Another barrier to influencing change outlined by the organisations was political will. They explained that most politicians do not want to support evidenced-based strategies if they require large investments over a period of time. This is because politicians are largely focused on election cycles and therefore, look for immediate solutions.

#### HSE resources

The last barrier to influencing change outlined by the organisations interviewed was HSE resources. The organisations explained that while they may successfully change policy, this means nothing if the HSE does not have the resources to implement it. The organisations highlighted autism policy and legislation as an example of this and outlined that lack of implementation is the main issue.

### **Impact of CSOs in Reducing Health Inequalities**

Civil society organisations have a significant impact in reducing health inequalities for parents, children and families affected by the case study conditions. For example, organisations provide access to therapies for children with autism. While some organisations provide these services on behalf of the HSE, other regional organisations fundraise to provide these services due to the long waiting times in the public sector. Organisations also provide much needed information about the conditions, as well as information on access to appropriate services and supports.

While autism organisations have a significant impact in terms of provision of information, services and advocacy, they have been less successful in terms of influencing policy. The Department of Health has recently held consultations with CSOs and healthcare professionals. However, those interviewed explained that they have attended many consultations before without any significant changes to service provision.

In terms of lung cancer, one consultant explained that they were very happy with the consultation process conducted by the NCCP. They outlined that additional resources were provided to each rapid access centre on an equitable basis. This was based on need determined by data collected from each of the centres. In comparison, this level of consultation was not reported by those working in the field of brain tumours.

## ***3.4 Germany***

### **Overview of Civil Society Organisations**

Civil society organisations in Germany vary considerably in their motivations, funding and operations. Thus, for analytical purposes, a typology was developed along these three dimensions (see figure 3.2). First, self-help organisations are often local and regional in their orientation and distributed all across Germany for different conditions. These groups and organisations are often led by patients, parents or relatives. Second, umbrella organisations administer and coordinate self-help groups at a higher level, normally, nationwide. Due to their function, they are smaller in number than self-help groups. Third, is other institutions that focus more on the academic and technical nature of the case study conditions, either by providing academic or therapeutic services. This category also includes medical societies that operate at the intersection of academia, policy and patients.

**Figure 3.2: A Typology of German Civil Society Organisations**

<i>Self-help</i>	<i>Umbrella</i>	<i>Academic &amp; therapeutic</i>	
<ul style="list-style-type: none"> <li>• Aspies</li> <li>• Bundesverband Selbsthilfe Lungenkrebs</li> <li>• Selbsthilfegruppe Gehirntumor</li> <li>• Regional and local organizations</li> </ul>	<ul style="list-style-type: none"> <li>• Autismus Deutschland</li> <li>• Allgemeiner Behindertenverband in Deutschland (ABiD)</li> <li>• BAG Selbsthilfe</li> <li>• National organizations</li> </ul>	<ul style="list-style-type: none"> <li>• Hamburger Autismus Institut</li> <li>• German Cancer Society (Deutsche Krebsgesellschaft)</li> <li>• German Cancer Aid (Deutsche Hirntumorhilfe)</li> <li>• National organizations</li> </ul>	Motivation
<ul style="list-style-type: none"> <li>• Membership fees (individuals)</li> <li>• Health insurance funds</li> <li>• Project-specific support from external actors</li> <li>• Donations</li> </ul>	<ul style="list-style-type: none"> <li>• Membership fees (organizations)</li> <li>• Health insurance funds</li> <li>• Project-specific support from external actors</li> <li>• Donations</li> </ul>	<ul style="list-style-type: none"> <li>• Membership fees (individuals, industry partners)</li> <li>• Health insurance funds</li> <li>• Project-specific support from external actors</li> <li>• Revenue from services and/or asset management</li> <li>• Donations</li> </ul>	Funding
<ul style="list-style-type: none"> <li>• Self-help: exchange of experiences, personal support through regular meetings</li> <li>• Providing information for patients</li> <li>• Public relations work</li> </ul>	<ul style="list-style-type: none"> <li>• Administration and coordination of self-help groups</li> <li>• Exchange and transfer of information</li> <li>• Public relations work</li> <li>• Consultancy</li> <li>• Comment on ongoing debates</li> </ul>	<ul style="list-style-type: none"> <li>• Health policy</li> <li>• Consultancy</li> <li>• Public relations work</li> <li>• Therapeutic services</li> </ul>	Services

Note: The typology is derived for analytical purposes only. In practice, civil society organisations may operate in different roles. For example, some umbrella organisations also provide self-help services. The examples given are classified by the authors based on interviews or information available online.

Source: Authors, based on information online and interviews

### Numbers and Geographical Distribution

In terms of number and geographic distribution, considerable inequalities exist both within and across the case study conditions. First, in terms of autism, the network of regional organisations, therapy centres and residences are much denser in the North and West of Germany relative to the East and South of Germany. The director of a nationwide umbrella organisation explained this is the result of historical developments: autism self-help groups and institutes first evolved in the 1970s in Hamburg and spread to different areas close by. In the South, autism organisations provided consultancy services and focused on self-help groups, rather than therapeutic centres. By contrast, the East lags behind since health care in the German Democratic Republic was underdeveloped.

Drawing on OncoMap, a public database that lists medical institutions specialised in cancer and certified by the German Cancer Society, we can also paint a picture on the distribution of organisations in cancer. Across all cancer entities, there are 1,032 self-help groups in Germany. For lung cancer, there are 58. Pertaining to neuro-oncology, including brain tumours, there are 52 self-help groups. Overall, the distribution of self-help organisations is determined primarily by a rural-urban split in that individuals in densely populated areas have more easily access to organisations than others. In terms of centres—a network of inpatient and outpatient facilities, working together in all specialties and involved in the treatment of cancer patients—1,845 centres meet the standards of the German Cancer Society (as per 11 June 2019). Of these, 68 can treat lung cancer and 37 work in neuro-oncology. A majority of these centres are university clinics and therefore located in cities, potentially giving rise to geographical inequalities.

Due to their national orientation and focus on administration and coordination of self-help groups, the distribution of umbrella organisations is unlikely to give rise to health inequalities. These institutions are located in big cities (for example, Berlin and Cologne), close to university clinics (for example, Heidelberg) or based in places with important therapy centres (for example, autisms Deutschland e.V. is based in Hamburg, where the first self-help group in Germany was set up in 1970).

### **Funding of CSOs**

The individual sources of funding for the three types of organisations are very similar, although the relative importance varies. For example, all organisations may levy membership fees. Yet self-help groups try to minimize these; some self-help groups do not charge anything at all or only to cover small expenses (such as coffee and tea). In contrast, for umbrella organisations and medical societies membership fees are more important.

Due to the legal status of a registered organisation in Germany (eingetragener Verein, e.V.) pertaining to health, all organisations can apply for annual funding from health insurance funds. Since 2008, health insurance funds have a legal mandate to provide financial support for self-help groups (§ 20c SGB V). In turn, this is the main source of income for self-help groups and covers rent and other expenses. Several interviewees mentioned the heavy workload associated with applying for funding and the waiting times until they would receive the money. For instance, a leader of a self-help group said:

*"By December, we had to apply for funding. Now it is almost the end of May and we are still waiting for the money, without knowing how much they will approve. We therefore need to bridge this gap ... one would need to interrupt the work until the receipt of the money, but of course we can't do that and need to find other solutions".*

Further, the organisations can supplement their resources with additional funding for specific projects, such as workshops or other public health initiatives. Self-help groups do so by approaching health insurance funds or representatives from industry. By contrast, umbrella organisations and medical societies may also obtain financing from dedicated trusts and foundations.

Lastly, medical and academic societies generate revenue from asset management too. For therapeutic centres, the main source of income is the provision of services, which is normally indemnified through health insurance funds or the Eingliederungshilfe (for autism in children). Finally, all organisations also rely on individual donations.

### **Services provided by CSOs**

Self-help groups primarily provide services to the direct benefit of their members. That is, their daily operations are targeted to help patients and their relatives navigate the complex health and social system. One core aspect of this are regular group meetings that facilitate the exchange of patients' experience with the condition, the discussion of problems that may arise in everyday situations and provide inspiration for others on how to best 'get on with life'. Particularly in autism, self-help groups also help with enforcing legal rights. For example, in terms of applying for disability benefits or when talking to school principals regarding the special requirements of children with ASD.

Umbrella organisations offer a different set of services. Primarily, they administer and coordinate self-help groups, thereby facilitating the exchange of ideas and the diffusion of best practices. In addition, these organisations speak to patients and the broader public at workshops that they host. Apart from

disseminating information to keep patients informed about relevant changes in the German health and legal system, umbrella organisations are also in contact with academics and doctors to draft statements aimed at policymakers. The Deutsche Hirntumorhilfe illustrates the broad range of tasks—discussed in Box 3.1.

*Box 3.1: Deutsche Hirntumorhilfe.* The German Brain Tumour Association (Deutsche Hirntumorhilfe) takes a three-pronged approach to improve the life of brain tumour patients. First, the organisation disseminates relevant information on brain tumour to patients and engages in public relations work. For instance, the Association publishes the magazine 'Brainstorm' which speaks to both patients (and their relatives) and doctors, featuring academic articles, interviews with doctors or stories from patients. Further, it initiated the World Brain Tumour Day in 2000, which is observed on 8 June every year to raise public awareness and educate the public about brain tumours. Second, the organisation supports self-help groups in different capacities. For example, it supports individuals to launch new self-help groups and connects leaders of such groups in national meetings (currently, twice a year). Finally, the Association works with academic partners to support research in neuro-oncology and builds networks and collaborations to connect stakeholders.

Therapeutic organisations and medical societies emphasize other aspects of the case study conditions altogether. Therapeutic centres predominantly provide diagnostic and therapeutic services and do not engage with patients in any other capacity or with the public. By contrast, medical societies, such as the German Cancer Society, invest considerable efforts in disseminating information on the latest advancements in research and health policy to both doctors and the general population. In addition, these organisations are heavily involved in health policy, by launching their own initiatives or by commenting on drafts of new bills. In addition, medical societies are regularly invited to meetings of the Federal Joint Committee to advise on areas of their expertise.

### Strategies and Challenges

The organisations employ different strategies to pursue their objectives. All self-help groups interviewed host regular meetings to facilitate the exchange of experiences amongst their members. In addition, they advise patients and their relatives at the point of contact in matters ranging from recommending doctors to applying for disability benefits. Beyond that, however, the strategies employed are largely ad hoc. This is both a strength and a weakness. On the one hand, it enables these institutions to be flexible and respond to temporary or newly arising issues. For example, this was the case when a cancer self-help group lobbied for advertisement space in the Berlin underground to observe World Brain Tumour Day. On the other hand, these ad hoc actions are time-consuming and resource-intensive since they are not standardised. However, while this appears inefficient in terms of economic resources, it is beneficial for patients and their relatives. In many cases, the leaders of self-help groups have considerable expertise in dealing with bureaucracies and this allows them to suggest solutions tailored to patients' needs.

Umbrella organisations rely on more formal governance processes to achieve their goals. Since the activities of coordination vary little over time, these processes are largely standardised. For instance, meetings and workshops are organised regularly. Likewise, whenever these organisations receive requests to participate in studies or comment on draft legislation, they forward requests to their members. In addition, the network of organisations, researchers and policymakers ensures that umbrella organisations have access to the relevant information for their activities.

Finally, the strategies of medical societies and therapeutic institutions are even more formalised and targeted. Both types of organisations employ staff—individuals with a background in social sciences



or medical training—to carry out the day-to-day operations. Nonetheless, learning by doing and the exchange with partners remain important.

The challenges these organisations face originate in the three dimensions—motivation, funding and services—discussed above. Common to self-help groups from all case study conditions are the following:

- Lack of resources: Interviewees reported a lack of resources both financially as well as in terms of personnel/members.
- Misleading or lack of media attention: While autism is increasingly covered in newspapers and film, it is still too often portrayed narrowly as a binary condition instead of a spectrum, according to several interviewees. In the case of brain tumour, lack of media attention is largely because of its relatively small incidence. In the case of lung cancer, this is in part due to the prevalent misconception that smoking is the only cause of lung cancer. One member of a self-help group suggested:

*"Both politicians and the media don't want to get involved. We invited several journalists and politicians to write a foreword for one of our information booklets... They don't want to speak to us... the stigma is too big. Politicians don't see the benefits of talking to us, a small self-help group in lung cancer. And that's it".*

- Stigma and insufficient understanding of the condition: While the public awareness of autism has increased in recent years, facilities—even at meetings of individuals with different disabilities—remain ill-suited to people with autism. In addition, individuals with autism need to renew their diagnosis and apply for disability benefits every four years, revealing an understanding of autism as an illness, rather than disability and chronic condition.
- Contribution to health policy: In recent years, members of self-help groups have been increasingly recruited to participate in academic studies on new development in autism and cancer. Nonetheless, the interviewees voiced concerns that their interests remain underappreciated in policymaking.

Most concerns of umbrella organisations, medical societies and therapeutic institutions are broader than those of self-help groups and include the following:

- Health policy effectiveness: By and large, the organisations interviewed are in regular contact with policymakers. In particular, CSOs are included in the legislative process in Germany already in the drafting stage, putting these organisations in a strong position to influence policy. Yet on many occasions CSOs compete with other, better-resourced actors, such as industry representatives and health service providers. Thus, it remains a challenge to put the patients' interests at the heart of debates on health policy reforms. For instance, one autism therapy centre was concerned about the neglect of their best practices at the expense of randomised control trials conducted at universities.
- Complexity: For autism, complexity is an issue because of the different actors involved. By contrast, treatment of cancer is increasingly complex because of the diverse forms within given cancer entities. Thus, such capabilities still need to be built and for patients with a given cancer, organisations may lack the knowledge to deal with it.



## Impact of CSOs in Reducing Health Inequalities

There are two mechanisms through which CSOs can reduce health inequalities. First, patients can directly benefit from the services that CSOs—particularly self-help groups—provide. Second, umbrella organisations and medical societies engage with the broader public and effect policy change. In doing so these organisations impact upon the macro-framework in which the diagnosis of treatment of the case study conditions take place.

### Service Provision

Self-help groups provide invaluable information to patients on how to navigate the process of diagnosis and treatment. That is, they accompany members of their groups throughout the course of the conditions, starting even before the diagnosis. In particular, they advise on which doctors or centres to consult for diagnosis of autism or cancer, respectively. Further, they support patients in enforcing their rights. In doing so, they level the playing field to put individuals less experienced with the social and health system in a better position to obtain a timely diagnosis and treatment.

In addition, they support patients in their daily lives and reduce health inequalities associated with the psycho-social ramifications of a diagnosis. An interviewee representing a medical society observed:

*"The German health system is well-equipped to diagnose and treat different entities of cancer. In addition, we gradually have come to realise the importance of the personal support of patients, but there is still a long way to go in that respect. Here, self-help groups play a very important role".*

### Policy Change

As discussed above, formally, there are different pathways through which patients with autism spectrum disorders and cancer can advocate for their needs. On the one hand, the national autism organisation autism Deutschland e.V. is a member of the German Council of People with Disabilities. On the other hand, other organisations also represent individuals with autism, although the constituents of these organisations are more diffused. For instance, the BAG Selbsthilfe works on behalf of 117 self-help groups to represent patients with disabilities, chronic illnesses and their relatives in the German Council of People with Disabilities. However, by and large, interviewees were critical of the GBA and felt their voice carried relatively little weight in discussions pertaining to autism. Further, as noted above, health policy is but one relevant area for individuals with autism.

Advocates of policies pertaining to cancer are represented similarly in the GBA. As a chronic condition, the BAG Selbsthilfe also represent the interests of their self-help groups. In addition, technological advancements in diagnostics and treatment as well as their financing are highly relevant. As a result, representatives from medical societies are regularly invited to contribute to relevant subcommittee and working group meetings in the GBA. One interviewee with several years of experience noted that:

*"Yes, we would be invited to these meetings. However, it sometimes felt as if the members of the committee had already made up their mind before...as if our role was to legitimize their decision".*

In addition to the formal structures of the health system, CSOs use informal or ad hoc modes to influence policy. In particular, in the development of drafting new laws or discussing guidelines, CSOs have featured prominently in their establishment, as we discuss in Box 3.2 on the S3 Guidelines that pertain to the diagnosis of autism spectrum disorders and Box 3.3 on the National Cancer Plan, respectively.

*Box 3.2: S3 Guidelines for Diagnosis of ASDs.* Although there are no central diagnostic guidelines for autism, the German Society for Child and Youth Psychiatry, Psychosomatic Medicine, and Psychotherapy (DGKJP) and the German Association for Psychiatry, Psychotherapy and Psychosomatics (DGPPN) developed the so-called S3 Guidelines for diagnosis of ASDs. Multiple actors from civil society contributed to the development of this interdisciplinary guideline, including autismus Deutschland e.V. and Aspies e.V., an umbrella organisation and nationwide self-help group, respectively. This guideline is an important element in the diagnosis of autism because it takes into account the variegated experiences of autism over the life-course and the different diagnostic tools that are relevant for different age groups of patients. Currently, the same organisations are working on a similar guideline for the treatment of autism, once again with the inclusion of CSOs to ensure that patients are represented.

*Box 3.3: National Cancer Plan.* The National Cancer Plan is another example of the role of civil society in the German health system. In 2008, the Federal Ministry of Health launched the German National Cancer Plan jointly with the German Cancer Society, German Cancer Aid and the Consortia of German Tumor Centres (Arbeitsgemeinschaft Deutscher Tumorzentren) as a response to the increasing prevalence of cancer in the German population. In drafting the Plan, actors from the Federal States to health insurance companies, from pension insurance to health providers and from academia to patient representatives were involved. In addition, CSOs remain crucial in the implementation of the Plan. For example, the German Cancer Society is part of a number of working groups. Expert teams defined 13 goals and around 40 sub-targets. For each of these, separate recommendations on how to achieve these goals were developed. Initially, the Plan focused on further developing cancer screening; improving the structural aspects of oncology care and quality assurance; ensuring effective treatment and strengthening patient orientation in cancer care. However, since its launch, it has extended beyond that. For instance, a milestone in the implementation of the Plan was the adoption of a new law in spring 2013 that provided the framework for the establishment of comprehensive clinical cancer registries by all the federal states of Germany. Moreover, under the new law, certain examinations for cancer screening will be conducted as organised screening programs in the future. This law was originally developed by a working group in parliament, set up by the German Cancer Society in cooperation with two politicians.

## 3.5 Spain

### Overview of Civil Society Organisations

In Spain, there are several types of civil society organisations providing services for the case study conditions – autism spectrum disorder, lung cancer and brain tumours.

First, Spain has 119 autism civil society organisations registered at the national registry of associations. Many of these organisations also form platforms at national level such as the Autism Confederation Spain, which brings together 77 associations. In addition, the Spanish Confederation of Parents-Guardians of People with Autism (FESPAU) groups together 25 associations whilst the Asperger Confederation of Spain has 27 partner civil society organisations (see figure 3.3).



**Figure 3.4** Number of associations according to confederation and autonomous community



Source: AECC 2019<sup>101</sup>

Third, there is also a wide network of patient and family associations that offer support and work towards comprehensive care policies, including health, education, labour, so that the different needs of the people affected by cancer and autism, among other conditions, are met. For example, the Spanish Committee of Representatives of People with Disabilities groups more than 8,000 organisations.

Fourth, in Spain professional societies also play a key role in addressing the needs of patients and keeping health care professionals informed and well trained. For example, the Spanish Society of Medical Oncology (SEOM) is a national non-profit scientific society, made up of more than 2,500 professionals in the field of Oncology, with the aim of improving the prevention, diagnosis, treatment and monitoring of cancer with a multidisciplinary approach. SEOM promotes studies, training and research activities, dissemination and information aimed at oncologists, patients and society in general. The Spanish Society of Public Health and Health Administration (SESPAS) is another example of a professional society where their members are integrated into SESPAS through 12 scientific societies. SESPAS mission is to contribute to population health whilst addressing health inequalities and to improve the quality of the Spanish Health System.

Finally, there are also a growing number of civil society organisations that are locally based and have novel ways of funding and providing services to people living with cancer and autism. These organisations specifically work in addressing stigma and have developed an activist approach by challenging the formal structures in which patients and families are treated (see Figure 3.5 below for a typology of Spanish CSOs).

**Figure 3.5: A Typology of Spanish Civil Society Organisations**

<b>Local activists</b>	<b>Self-help</b>	<b>Umbrella</b>	<b>Academic &amp; therapeutic</b>	
<ul style="list-style-type: none"> <li>Local organisations</li> </ul>	<ul style="list-style-type: none"> <li>Patient and family organisations</li> <li>Spanish Association Against Cancer</li> <li>Spanish Association of Lung cancer</li> </ul>	<ul style="list-style-type: none"> <li>Autism Confederation Spain</li> <li>Spanish Confederation of Parents/Guardians of people with Autism (FESPAU)</li> <li>Asperger Confederation of Spain</li> <li>Federacio Catalana d'Entitats</li> </ul>	<ul style="list-style-type: none"> <li>National organisations</li> </ul>	Motivation
<ul style="list-style-type: none"> <li>Membership fees (individuals)</li> <li>Donations</li> <li>Local authorities funding</li> </ul>	<ul style="list-style-type: none"> <li>Membership fees (individuals)</li> <li>Government funding</li> <li>Project-specific support from external actors</li> <li>Donations</li> </ul>	<ul style="list-style-type: none"> <li>Membership fees (organisations)</li> <li>Government funding</li> <li>Project-specific support from external actors</li> <li>Donations</li> </ul>	<ul style="list-style-type: none"> <li>Membership fees (individuals, industry partners)</li> <li>Project-specific support from external actors</li> <li>Revenue from services and/or asset management</li> <li>Donations</li> </ul>	Funding
<ul style="list-style-type: none"> <li>Awareness, information provision, campaigning addressing stigma</li> </ul>	<ul style="list-style-type: none"> <li>Self help: exchange of experiences, personal support through regular meetings</li> <li>Information provision</li> <li>Public relations work</li> </ul>	<ul style="list-style-type: none"> <li>Administration and coordination of self help groups</li> <li>Exchange and transfer of information</li> <li>Public relations work</li> <li>Research and advocacy</li> </ul>	<ul style="list-style-type: none"> <li>Health policy</li> <li>Consultancy</li> <li>Public relations work</li> <li>Therapeutic services</li> <li>Research</li> </ul>	Services

### Funding of CSOs

In Spain, civil society organisations receive funding from several sources. This includes private funding provided by private corporations, banks, individual donations, and public funding available from the European Union, Central Government, Autonomous Communities and local entities. Not all civil society organisations receive public funding, in some cases they access in-kind benefits such as having access to facilities provided by the local council.

Civil society organisations normally receive funds through the Official Development Aid (ODA), which is the public funding provided by Government. However, the budget allocated to ODA was reduced disproportionately relative to other sectors as a result of the financial crisis and austerity measures<sup>102</sup>. According to Oxfam, ODA funding decreased by 53 per cent in the past four years<sup>103</sup>. Participants corroborated the fact that austerity measures and the closure of some of the "Social Banks (Cajas)" had affected their ability to raise funds and to implement the programmes which were operating before the financial crisis hit Spain.

The second most important source of funding comes from the income tax revenues that the state obtains from Personal Income Tax. A total of 0.7 per cent is assigned to civil society organisations to design their social programmes. This budgetary line provides the funding to the Spanish Ministry of Health, Social Affairs and Equality to fund entities undertaking programmes such as those related to cancer and autism.

However, recently, the model of funding has been called into question because of the way the 0.7 per cent of Personal Income Tax is disbursed to Autonomous Communities. A new distribution model has been adopted, whereby the National Government manages 20 per cent of the funds while the Autonomous Communities are responsible for managing the remaining 80 per cent. Concerns have been raised that some Autonomous Communities might decide to allocate part of the funds from the 0.7 per cent to their general budgets<sup>104</sup>.

Participants reflected on this new way of funding and were concerned that some programmes that had been funded for many years at the national level were not considered a priority at the regional level



and as a result, funding had stopped and programmes were put on hold. The following is an example of such accounts:

*"When we were working with the Ministry we were doing well. Now that they have passed the funding to the autonomous communities... it has been a disaster. For example, a project called "Much to live", a project for the rehabilitation and improvement of the quality of life of women diagnosed with breast cancer... received funding from the Ministry and it has now been stopped."*

Overall, participants working in the prevention and treatment of cancer mentioned several programmes that had been funded nationally for a number of years. However, in the area of autism, several interviewees found it difficult to access public funds and therefore have insufficient resources to conduct their activities.

### **Services provided by CSOs**

In relation to autism, the main services provided by civil society organisations include information provision and training of families. Other services include clinical diagnostic services, day centres and independent residential facilities for adults with autism. Interview participants reported that while autism organisations in cities such as Madrid are well organised and coordinate with the administration, those based in smaller towns tend to be isolated and do not have sufficient resources and support to conduct their activities.

With regards to cancer, the main services provided by CSOs include medical advice, cancer screening, awareness campaigns, health promotion and training. Cancer organisations also provide services where volunteers help patients by carrying out activities such as buying food or helping with domestic chores, while for patients in remote areas, they provide transport to healthcare appointments. In addition, some organisations offer specialised psychological care such as psycho-oncology, which is not available in the public health system. These services are normally offered at no cost to the patient. However, the possibility of accessing different services varies depending on the capacity of the organisations and where the organisation is located. Finally, participants noted that both cancer and autism CSOs now undertake their own research activities.

Overall, interviewees reported that CSOs in Spain provide services that might be considered essential within the public health systems of other countries. However, they highlighted that these services are not offered consistently across the country, but rather are concentrated within the larger cities. Participants explained that one of the reasons for this is that civil society organisations find it harder to establish in smaller cities. For example, it was suggested that the Association of Asperger in Lleida (a small town in Catalonia) found it much more difficult to establish and receive funding compared to similar organisations in Barcelona or Madrid. It was emphasised that being based in a small town made it much more difficult to get noticed. With regards to cancer, access to CSOs differed according to cancer type. For example, it was reported that patients with brain tumours had less access to CSOs, and thus less services and representation, than those with more common types, such as lung cancer.

### **Impact of CSOs in Reducing Health Inequalities**

Civil society organisations in Spain play a crucial role in reducing health inequalities for those affected by the case study conditions. In terms of service provision, CSOs provide a range of services. With regards to autism, they provide much needed information to families and in some cases, also provide clinical diagnostic services. These services help to reduce inequalities in access to diagnosis. CSOs

also provide a range of services for patients affected by cancer. For example, they provide transport to healthcare appointments for those living in remote areas, which have a direct impact on the patients' ability to access healthcare services. While some interviewees felt these services were essential and as such, should be funded by government and provided through the National Health System, most agreed that civil society organisations play a crucial role in reducing health inequalities and should be supported further.

In general, participants reported that CSOs did not have a substantial impact on government policies. This was highlighted particularly by smaller CSOs which suggested that it was very difficult to get noticed and supported financially, let alone have an influence on the policy making process:

*"Politicians and people just want to know how many partners you have, and then we are a small and humble society [...] you go talk to so and so...and you are talking to everyone and the first years you do it, and then you get tired because you say, well they are making me dizzy, and at the moment of truth, they don't give you anything [funding], because we finance ourselves with pins, with lottery, with donations, but from the administration nothing. Nothing."*

Despite this, some examples of policy influence were reported. These included the participation of civil society organisations in the Cancer Strategy and the national autism strategy. In addition, civil society organisations more broadly played a crucial role in derogating article Royal Decree-law 16/2012 and granting undocumented migrants with the right to health protection and healthcare.

### **3.6 Conclusion**

This chapter outlined the role that CSOs have in reducing health inequalities. Specifically, it identified two pathways through which CSOs can reduce health inequalities for those affected by the case study conditions. The first is a direct pathway, where the services provided by CSOs directly benefit patients and their families. The second is an indirect pathway in which CSOs try to influence policy.

With regards to the direct pathway, the chapter highlighted that CSOs in all three countries had a significant impact in terms of reducing health inequalities for those affected by the case study conditions. Common services provided by CSOs across the three countries include: information provision, advocacy work, support groups, diagnostic services and therapies, residential care and respite and transport to healthcare appointments. In terms of autism, information provision by CSOs was significant in addressing the difficulty in navigating the pathways to diagnosis and treatment that was reported in all three countries.

Civil society organisations also tried to reduce health inequalities indirectly by influencing policy. However, whether or not they had an impact on policy tended to be reflected in the size of their organisation. For example, in Germany, umbrella organisations and medical societies had a significant impact on policy. This was due to their perennial experience and formal involvement in the legislative process. This was found to a lesser extent in Ireland, where select umbrella and national organisations are involved in the development of policy but in a less formal and less transparent way.

In comparison, smaller organisations across the three countries did not have a significant impact on government policy. In particular, autism organisations and brain tumour organisations outlined that a lack of representation by, or engagement with, larger national and umbrella organisations was a barrier to influencing policy. One exception to this can be found in local autism organisations in Ireland. These organisations have established around an urgent demand for services such as day centres in the local area. While the initial focus of these groups was to secure services rather than policy changes, the groups have had a significant impact in terms of gaining access to government Ministers, having their activities reported in national media and securing the needed services.

Therefore, autism, lung cancer and brain tumour CSOs in all three countries have directly reduced health inequalities for patients and their families through service provision. In terms of policy, Germany was found to have the most significant impact. This is due to the formal structures within the German health system that facilitate communication with policymakers by including organisations in the legislative process.



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# 4. Reducing Health Inequalities: The Role of the EU

# 4. Reducing Health Inequalities: The Role of the EU

## *Chapter Outline*

The previous chapters have described the health system in each of the three countries and outlined how these systems create or contribute to inequalities in access to services for the case study conditions. This chapter moves beyond national health systems to explore EU health policies and the role they have in reducing health inequalities.

## *EU Health Policy*

Member states are responsible for the organisation and provision of healthcare to EU citizens, while the role of the EU is to complement national policies<sup>105</sup>. For example, in areas where Member States cannot be effective alone, such as pandemics, bioterrorism and health threats relating to the free movement of goods, services and people, cooperative action at EU level is essential. While actions on health can be found in various EU Treaty articles, due to 'several growing challenges to the health of the population' a European Community (EC) Health Strategy was deemed necessary<sup>106</sup>.

The first EC Health Strategy, *Together for Health: A Strategic Approach for the EU 2008-2013*, was published in 2007. It outlined three growing challenges to the health of the European people including population ageing, threats to health such as climate change, pandemics and bioterrorism and new technologies. In order to tackle these challenges, *Together for Health* set out a coherent framework including four core principles and three strategic objectives to direct community activities in health until 2013.

The core principles outlined include a strategy based on shared health values, links between health and economic growth, integration of health in all policies and strengthening the EU's voice in global health. The three strategic objectives include fostering good health in an ageing Europe, protecting citizens from health threats and supporting dynamic health systems and new technologies. Although originally developed for the period 2008-2013, these principles and objectives as outlined in the strategy remain valid and are aligned with the overall Europe 2020 strategy<sup>107</sup>.

The EC mandate to reduce inequalities in health is outlined in the first core principle of the Health Strategy. This principle advocates a value-based approach and aims to build on the Council Conclusions on Common Values and Principles in the European Union Health Systems which includes overarching values of universality, access to good quality care, equity and solidarity<sup>108</sup>. In addition, it outlines that a value-based approach must focus on reducing health inequalities, as major inequities continue to exist between and within Member States, as well as globally. The list of actions resulting from this first

principle of the Health Strategy includes undertaking further work on how to reduce inequities in health.

In response to this action, the Commission produced the communication '*Solidarity in Health: Reducing Health Inequalities in the EU*'. This document outlines that further action to reduce health inequalities is needed due to the 'size and pervasiveness of health inequalities across the EU' and 'concerns about the negative consequences for health, social cohesion and economic development' if the issue of health inequalities is not addressed<sup>109</sup>. The communication provides an overview of health inequalities in the EU and outlines the current EU policies that aim to address these. In addition, it highlights a number of key issues which need to be addressed to reduce health inequalities, including meeting the needs of vulnerable people and gaining commitment across various stakeholders in society who have a role in reducing health inequalities. Reducing health inequalities has also featured as an important goal for the EU in *Investing for Health* (2013), which outlines the role of health in the Europe 2020 policy framework.

### ***European Pillar of Social Rights***

In addition to the above policies which focus specifically on health, the EU has recently endorsed the European Pillar of Social Rights. The European Pillar of Social Rights is about delivering new and more effective rights for citizens. It has 20 key principles, which are structured into 3 main categories: equal opportunities and access to the labour market, fair working conditions and social protection and inclusion. Healthcare is the 16th principle and is dealt with under social protection and inclusion. It states that 'everyone has the right to timely access to affordable, preventive and curative health care of good quality'<sup>110</sup>.

In terms of making the European Pillar of Social Rights a reality, the EU outlines that it is a joint responsibility. They note that most of the tools for delivery are in the hands of Member States, as they are responsible for the organisation and provision of healthcare to EU citizens. They also explain that social partners and civil society are important for the delivery of the pillar while the role of the EU institutions is to set the framework and provide direction.

### ***Role of the EU in Health***

Following this brief overview of EU health policy and the European Pillar of Social Rights, the main role of the EU institutions in health is to provide direction to Member States in order to increase access to healthcare, reduce inequalities and create sustainable health systems. In addition to this, EU institutions also build cooperation between Member States for cross-border issues, such as those relating to the free movement of goods, services and people.

### ***Protecting Civil Society***

While Chapter 3 detailed how civil society organisations reduce inequalities at national level, an examination of EU health policy highlights the important role of CSOs in advocating for European policies that reduce inequalities.

The importance of CSOs has already been acknowledged in the European Commission Communication *The roots of democracy and sustainable development: Europe's engagement with Civil Society in external relations* (2012). The document puts forward three priorities for the EU to support CSOs:

1. Enhance efforts to promote a conducive environment for CSOs in partner countries.
2. Promote meaningful and structured participation in programming and policy processes to build stronger governance and accountability at all levels.
3. Increase local CSOs' capacity to perform their roles as independent development actors more effectively.

However, this report finds that for civil society to continue having an effective role in reducing health inequalities, further support from the EU is needed especially in terms of improved and simplified access to EU funding and grants. For example, there is a strong reliance on state funding for CSOs in Ireland and Spain. However, this funding has decreased significantly since the financial crisis (in Ireland, state funding for the voluntary and community sector fell by 32.2 per cent since 2008). In addition, annual funding applications and new governance measures have placed an additional burden on organisations, especially smaller CSOs. Improved access to EU funding and grants, especially multi-annual funding, would help to address the reliance on state funding for these CSOs.

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# 5. Conclusion and Policy Recommendations

## 5. Conclusion and Policy Recommendations

This report outlines inequalities in access to healthcare services in Ireland, Germany and Spain and analyses the role that civil society organisations (CSOs) have in reducing these inequalities.

Chapter 2 began with an overview of the health systems in Ireland, Germany and Spain. This allowed for clarity regarding the different types of health care systems in each of the European countries. It was highlighted that eligibility to healthcare in Ireland is not universal and is based primarily on residency and means. In contrast, Spain has a National Health Service and German healthcare is based on a Social Insurance System – which both provide near-universal coverage.

This chapter also examined inequalities within each of the health systems, which was addressed through a case study approach. This approach focused on access to diagnosis for three conditions: lung cancer, brain tumours and autism spectrum disorder. The chapter found that in Germany and Spain – where healthcare coverage is almost universal – inequalities in relation to access to diagnosis for lung cancer and brain tumours were mainly geographical. In comparison, in Ireland, inequalities in access to diagnostic services were both due to geographic and socio-economic variation. In all three countries, the experiences of accessing diagnostic services for autism were similar. Participants in Ireland, Germany and Spain found it difficult to navigate the assessment process and reported wait times of up to 2 years.

The findings from this chapter suggest that health systems with universal coverage reduce inequalities based on socio-economic grounds for certain conditions, such as cancer. For conditions such as autism, the type of health system was not a significant factor in reducing inequalities. However, it found that the ability to pay to access services privately as well as 'health literacy' – the knowledge of how to navigate the health system – contributes significantly to socio-economic inequalities.

Chapter 3 analysed the role that CSOs have in reducing health inequalities across the three countries. It identified two pathways through which the CSOs reduce health inequalities – directly through service provision and indirectly by influencing policy.

With regards to the direct pathway, this chapter found that the capacity of CSOs to reduce health inequalities was significant in all three countries. Autism, lung cancer and brain tumour CSOs in Ireland, Spain and Germany reduce health inequalities by providing services directly to patients and their families. The most common services provided by CSOs across the three countries were: information provision, advocacy work, support groups, diagnostic services and therapies, residential care and respite, and transport to healthcare appointments.

In terms of the indirect pathway, CSOs try to reduce health inequalities indirectly by influencing policy. This chapter found that the size of the organisation tended to reflect whether or not CSOs had an impact on policy. For example, while umbrella organisations and medical societies had a significant impact on policy, smaller organisations across the three countries did not. The chapter found Germany to have the most significant impact on policy due to the formal structures within the German health system that facilitate communication with policymakers and engagement with the legislative process.

Chapter 4 discussed the role of the EU in reducing health inequalities. It found that while the EU institutions set the framework and provide direction, most of the tools to reduce health inequalities are in the hands of Member States, social partners and civil society. Focusing particularly on the role of civil society, it outlined that further support from the EU is needed for civil society to continue having an effective role in reducing health inequalities.

## ***Recommendations***

The report makes the following country-specific recommendations:

### **Ireland**

- Establish a universal, single tier health service based around the principles of timely access and care driven by need rather than the ability to pay. This is enshrined in the recent Sláintecare report and is particularly relevant to reducing health inequality in terms of socio-economic factors. There must be investment and a prioritisation of public healthcare in order to achieve this recommendation. The influence of the private sector in Irish healthcare has a significant impact on equity, affordability and quality of healthcare. Although private healthcare has played a role in terms of addressing demand, it is of the utmost concern to the implementation of universal healthcare in Ireland to reduce the amount of state funding being channelled into private-for-profit health care providers.
- Provide clear pathways to diagnostic services and therapies for people with autism.
- Ensure policies to improve access to diagnostic services and therapies for people with autism are fully implemented and resourced.
- Moderate geographic variation in access to diagnostic services by increasing access to diagnosis at the community level.
- Reduce waiting times for first outpatient department appointment in the case of brain tumour diagnoses.
- Improve access to funding for CSOs. Specifically, provide access to multi-annual funding.
- Develop a formal and transparent framework through which CSOs participate in policy development and implementation strategies.
- Promote increased engagement and representation among organisations within the civil society sector.

### **Germany**

- Moderate geographic variation in the provision of health services. While access to health and diagnostic services in larger cities and university towns is adequate, the lack of such facilities in rural areas gives rise to health inequalities.
- Increase investment in training of medical staff. The case study conditions have highlighted the shortage of key personnel in diagnosis and treatment, such as psychiatrists or psycho-oncologists.
- Spend more resources on campaigns to disseminate information on health challenges and conditions to reduce misconceptions of illnesses. For instance, despite recent efforts, individuals with disabilities continue to face stigma from the public and the media.

- Reduce the complexity of the German health system. The German health system involves multiple actors, overlapping responsibilities and different levels of policymaking. Individuals and organisations with higher health literacy find it easier to navigate through the system, thereby exacerbating health inequalities.
- Increase representation of German CSOs in the governance of the German health system, including the Federal Joint Committee. By giving CSOs a right to vote (and not only to participate), these organisations can better compete with other actors, such as industry representatives and health service providers. This ensures that the patients' interests are at the heart of health policy reforms.
- Facilitate access to funding for CSOs. While funding is available for self-help groups, both the application and disbursement stages should better account for the resources and needs of CSOs.

## Spain

- Dedicate more research funding to estimate the prevalence of autism and to review why there are significant regional differences in mortality rates for cancer.
- Address regional inequalities by standardising the provision of treatment and available diagnostic tools for both autism and cancer across all regions. Key areas to address are the centralisation for cancer services that are not needed in a high volume (brain tumours), improving diagnosis services for autism and addressing the growing smoking incidence in women.
- Better organisation of cancer services to ensure that patients can receive the treatment they need in one healthcare facility rather than having to attend multiple locations to receive treatment.
- Provide public autism services with a multidisciplinary team and make sure appropriate follow-up and continuous care are provided.
- Take into consideration extra costs incurred by patients when living with cancer or autism (especially for the most vulnerable economic groups) and provide assistance when needed.
- Take into account gender inequalities in the prevention and treatment of both cancer and autism.
- Overall, there is a need to improve the organisation of oncological and autism diagnosis and care; coordinate the different specialists needed; and coordinate the different levels of care and follow-up.
- CSOs are providing key services for people living with cancer and autism and these organisations need to be appropriately supported. This includes funding for small organisations in smaller towns.
- CSOs have been involved in the Spanish strategies to address autism and cancer. There is a need to include them in the monitoring and evaluating processes.
- Ensure that CSOs are not prohibited by government funding from engaging in advocacy or experience any repercussions for critiquing policy.
- Design better pathways and involve CSOs in the design, implementation and evaluation of policies.



- Review funding disbursements from the national to the regional level to ensure fundamental programmes are not lost when the policies and process change.

The report also makes the following EU level recommendations:

- Full implementation of the European Pillar of Social Rights. This report found significant socio-economic inequalities in Ireland particularly, but also in Spain and Germany in relation to autism care. The implementation of the European Pillar of Social Rights - especially the right to timely access to affordable healthcare - would help to reduce these socio economic health inequalities.
- Improved and simplified access to EU funding and grants, especially multi-annual funding, which would help to lower the reliance on state funding for CSOs.



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# Appendix

# Appendix

## ***Data Collection***

Semi-structured interviews were conducted with civil society organisations, healthcare professionals and policy makers across the three countries. Roundtable events were held in both Ireland and Spain. At these events, members from relevant civil society organisations and policy makers were invited to provide feedback on the initial findings of the study and to contribute to policy recommendations.

Interviewees and roundtable participants were considered eligible to participate in the research if they had experience addressing health inequalities or were members of civil society organisations working in the areas of the three case study conditions – autism, lung cancer and brain tumours. Participants were provided with an information sheet and a consent form prior to participating in the study. These confirmed that any information would only be handled by the research team, stored securely and used only for the purposes of this study. Participants were also informed of the confidentiality and anonymity of their responses. To ensure confidentiality, neither the participant's name nor the name of their institution were included in any documentation related to this report. All interviewees gave consent for the interviews to be audio-recorded. The interviews lasted between thirty and ninety minutes. The roundtable discussions lasted approximately two hours. All audio recordings were transcribed and analysed thematically.

## ***Participant Details by Country***

### **Ireland**

As part of the Irish data collection, semi-structured interviews were conducted with 22 participants between April 2018 and May 2019. Of those interviewed, 16 were members of civil society organisations (CSOs), four were healthcare professionals and two were policy makers. In addition to the semi-structured interviews, a roundtable event was held in April 2019 with 14 participants. The initial findings from the Irish research were presented at the roundtable, with feedback welcomed from all participants. In order to facilitate discussion, the Chatham House rule was in operation. The roundtable lasted two hours and data collected during the event was merged and analysed along with the interview data. The roundtable consisted of 11 participants from CSOs and three academics.

### **Germany**

For the German data collection, semi-structured interviews were conducted with 13 participants between March 2019 and June 2019. All participants were members of civil society organisations that provide services pertaining to the case study conditions outlined in this report.

### **Spain**

A total of 32 participants took part in the study. Semi-structured interviews were conducted with 21 interviewees between November 2018 and July 2019. The breakdown of those interviewed is as follows: four policy makers, eight from CSOs, seven healthcare professionals, one from academia and one in the school sector. Also, 11 participants took part in a roundtable event. These discussions lasted approximately two hours and the participants were made up of three policy makers, three academics, three civil society organisations and two healthcare professionals.

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This report analyses inequalities in access to diagnostic services across three European countries – Ireland, Germany and Spain. Using a case study approach, it finds that socio-economic inequalities are more likely to affect access to diagnosis where health coverage is not universal. In addition, the report examines the role that civil society organisations (CSOs) have in reducing health inequalities. It finds that CSOs reduce health inequalities in two ways – directly through service provision and indirectly by influencing policy. However, it identifies a number of challenges for CSOs, and outlines that for civil society to continue having an effective role in reducing health inequalities, further support from the state and EU is needed.



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