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## The Role of Academics in Shaping EU Disability Law: Some Personal Reflections

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### 1. Introduction

My interest in European disability law existed almost before what is now the European Union (EU) actually adopted such law. In 1993, I defended my Ph.D., entitled *More Disabled Than Others – The Employment of Disabled People within the European Community: An Analysis of Existing Measures and Proposals for Reform*, at the European University Institute.<sup>1</sup> Amongst other things, the thesis looked at a variety of soft law instruments, including programmes ‘for’ or ‘to assist’ disabled people, as well as a proposal for a Directive on the minimum requirements to improve the mobility and safe transport to work of workers with reduced mobility.<sup>2</sup> However, there was little hard law to discuss and analyse. Instead, I reflected on the kind of legislation the then European Community could adopt, including what seemed like a pipe dream at the time: a European directive prohibiting disability discrimination in the field of employment. I have subsequently, and only half jokingly, described my Ph.D. as a work of fiction, in that, at the time, there was no European disability law to analyse and no academic literature on the topic to study.

More than thirty years on from my defence, the situation has changed significantly. The Treaties, as well as the EU Charter of Fundamental Rights, explicitly refer to disability, and the EU has explicit competence to adopt legislation addressing the needs of persons with disabilities; there is a wide body of both mainstream

\* This chapter is dedicated to the memory of Aart Hendriks. Aart was a pioneer in academic research on European and Dutch disability law and his work contributed to the development of EU law in this field.

<sup>1</sup> My PhD was subsequently published as L Waddington, *Disability, Employment and the European Community* (Maklu 1995).

<sup>2</sup> European Commission (Commission), ‘Proposal for a Council Directive on Minimum Requirements to Improve the Mobility and the Safe Transport to Work of Workers with Reduced Mobility’ COM(90) 588 final.

and disability-specific EU legislation that addresses disability, and that legislation includes a directive prohibiting disability discrimination in the field of employment (Directive 2000/78/EC);<sup>3</sup> there is an ever growing body of case law on disability from the Court of Justice of the European Union (CJEU);<sup>4</sup> the EU is a party to the United Nations Convention on the Rights of Persons with Disabilities (CRPD);<sup>5</sup> and disability law, and European disability law, has attracted the attention of a wide range of scholars, and is the subject of monographs and journal articles. Throughout that time, I have worked as an academic specialising in, *inter alia*, European disability law at Maastricht University, which is located conveniently closely to Brussels and the European institutions and civil society organisations based there. I have also worked with European Organisations of Persons with Disabilities (OPDs), including the European Disability Forum (EDF), the European Commission and representatives of other EU institutions. That work has frequently concerned the development of European disability policy and law. In 2004 I was appointed Professor of European Disability Law, and my Chair was established in cooperation with EDF.

This chapter concerns the role of academics in shaping EU disability law. However, it does not set out to reflect and analyse the role which academics play in general in shaping EU disability law. It is not based on semi-structured interviews or focus groups with academics and EU policy makers reflecting on the contribution of academics to EU disability law. Its goal is simpler and more personal than that – to reflect on my own 30 year plus experience as an academic working with EU policy makers, OPDs and fellow academics on projects and initiatives relevant to EU policy and law, as well as to present information on the experiences of some of the fellow academics who I work with and who were kind enough to discuss their thoughts with me, or provide me with other relevant information.<sup>6</sup> In that sense the chapter discusses EU law and policy in context and recognises the various ways in which academics can influence that law and policy.

I acknowledge that I was first hesitant to write such a contribution, since I prefer to reflect on legal and policy developments in my writing, rather than on my own experiences and that of colleagues and friends. However, I eventually decided to write this chapter after recalling reading and learning from an autoethnographic paper written by Stefan Trömel on the drafting history of the CRPD.<sup>7</sup>

<sup>3</sup> Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation [2000] OJ L303/16.

<sup>4</sup> B Cortese, 'The Role of the Court of Justice of the European Union in Protecting Disability Rights' in this volume.

<sup>5</sup> Council Decision 2010/48/EC concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities [2010] OJ L23/35.

<sup>6</sup> I am grateful to the following colleagues who discussed their work with me or provided me with relevant information: Dr David Gutiérrez Colominas, Universitat Autònoma de Barcelona; Professor Rune Halvorsen, Oslo Metropolitan University; and Emeritus Professor Mark Priestley, Leeds University.

<sup>7</sup> S Trömel, 'A Personal Perspective on the Drafting History of the United Nations Convention on the Rights of Persons with Disabilities' in G Quinn and L Waddington (eds), *European Yearbook of Disability Law Volume 1* (Intersentia 2009) 115–138.

Stefan had attended all meetings of the Ad Hoc Committee in his capacity as director, and then advisor, to EDF, and his paper provided insights not found elsewhere in the literature. I hope that this chapter will be equally as interesting to some readers.

This chapter is structured as follows. Section 2 discusses the various ways in which academics can contribute to EU (disability) policy making and law in a generic sense. These are explored in more detail in the subsequent sections. Section 3 therefore explores the contribution of academics to EU disability law and policy through working with the European Commission, and in particular through the work of the Academic Network of European Disability experts (ANED) and its successor, the European Disability Expertise network (EDE). Section 4 looks at the contribution of academics to EU law through working with the following European institutions and bodies: the European Parliament (EP), the CJEU and the Member States holding the Presidency of the Council of the EU (Council). Section 5 considers the indirect influence that academics can have on EU disability law and policy through their collaboration with OPDs, including with EDF in particular. Section 6 considers the contribution of academics to EU disability law and policy through EU funded research programmes. In all cases, I do not claim to give a thorough overview of the work and actions of academics in these fields. Instead, I am largely reflecting on my own experience and that of the academics who I have worked with. Section 7 provides some concluding remarks.

## 2. Academics and ‘Points of Entry’ to Impact on EU Disability Law and Policy

Two of the core tasks of academics – namely teaching and research – can, at most, influence EU law and policy in very indirect and uncertain ways. It is possible that some of our students will go on to work for an EU institution, Member State government or civil society organisation – and I have indeed been privileged to see some of my students go on to work on EU disability law and policy at the EU or national level – or that our research will be read by legislators and policy-makers, and will influence their action in some way. Bruno De Witte has described the former trend in the following way:

EU law scholars must necessarily take an interest in the activities of the legal practitioners in the EU institutions in order for their teaching to be relevant. Through their teaching, they diffuse legal knowledge to new generations of jurists and that knowledge will then indirectly affect the work of the EU institutions when some of the students become practitioners in the EU institutions.<sup>8</sup>

<sup>8</sup>B De Witte, ‘Editorial Note: How Much Critical Distance in the Academic Study of European Law?’ (2022) 18 *Croatian Yearbook of European Law & Policy* X.

However, in addition our work can have ‘societal impact’ in other ways, including when we collaborate with policy-makers and civil society. In the context of EU disability law and policy, a number of ‘entry points’ – or areas in which academics can interact with those influencing law and policy – have opened up over the past thirty years.

Firstly, following discussions over a number of years, the European Commission launched a tender for ANED in 2007, and the first network was established in December 2007.<sup>9</sup> This pan-European academic network supported the development of disability policy by collaborating with the Commission’s Disability Unit. A network of this nature has continued to exist since then, with a number of short *hiatus* between calls for tenders, and with some changes being made when the network became EDE in 2020. As of 2014, the Commission has also funded the European Network of Legal Experts on Gender Equality and Non-Discrimination. Some work of this network is particularly relevant to disability equality law. Prior to 2014, two networks, one on non-discrimination generally, which included the disability strand,<sup>10</sup> and one on gender equality, existed. Going even further back, to the end of the last century, the Commission funded ground-specific networks, including a network on disability equality. From a disability perspective, the network provides the Commission with independent advice on disability discrimination in light of the Employment Equality Directive.<sup>11</sup> Both the ANED/EDE network and the Non-Discrimination network are funded via ‘service contracts’ to the Commission, in that the networks provide services tailored to meet the needs of the Commission. The Commission has also funded a number of other service contracts, often to produce reports on disability specific issues, over the years. In general, it is academics who carry out the research under these contracts, although other individuals, such as lawyers and members of human rights organisations, can also be involved. Funding for this kind of work, as well as academic research that is funded, for example, through the EU research funds, are both identified by Bruno De Witte as ways in which academics and (legal) practitioners in the EU institutions engage in ‘co-production of EU law knowledge’.<sup>12</sup> I have been privileged to be a member of all the aforementioned networks since they were established.

Secondly, in addition to working with the Commission, academics also work with other EU institutions on disability law and policy issues. This can include providing advice to individual Members of the European Parliament (MEPs) and helping them to draft proposed amendments to legislation; speaking on disability at events organised by the Parliament; and drafting reports for Parliamentary

<sup>9</sup> ANED, ‘About us’ available at <<https://www.disability-europe.net/about-us>>.

<sup>10</sup> Established in 2004. European Equality Law Network, ‘About us’ available at <<https://www.equalitylaw.eu/about-us>>.

<sup>11</sup> For reasons of space, the work of the European Network of Legal Experts on Gender Equality and Non-Discrimination is not discussed further in this chapter.

<sup>12</sup> De Witte (n 8) VII.

Committees on disability-related issues. The work of academics may also be considered by Advocates General and Judges at the CJEU, although this is not always explicitly acknowledged in their Opinions or judgments. Moreover, Member States holding the Presidency of the EU Council may collaborate with academics when developing their programme or when organising events on disability.

Thirdly, academics can partner with OPDs. They can provide legal and other advice and contribute to documents that call for changes to EU law and policy. This advice can range from an analysis of the competences the EU has to act, to drafting a fully developed proposal for legislation that the OPD can present to legislators and campaign around.

Lastly, research projects funded by the EU under its flagship research fund, currently Horizon Europe, can also relate to disability and have the goal, *inter alia*, of producing recommendations for policy-makers. Such research is generally led and largely carried out by academics, although it can also involve OPDs and individuals with disabilities.

### 3. The European Commission and Academics – Academic Network of European Disability Experts and European Disability Expertise Network

Academics who worked on disability from a human rights perspective initiated discussions on the establishment of a European academic network on disability as early as 2000. At that stage the network was not envisaged as a tool to support policy-makers, but rather as a research network on disability studies that could also offer a Master programme. In 2000, a number of academics, including Mark Priestley of Leeds University, Jan Šiška of the Charles University in Prague, Geert Van Hove of the University of Ghent and Catherine Barral of the Centre Technique National d'Etudes et de Recherche sur les Handicaps et les Inadaptations in France met in the Belgian town of Blankenberg to discuss setting up such a network.<sup>13</sup>

The possibility of the European Commission funding such a network, with a view to the network providing support for the Commission's work, also arose, and some academics quietly lobbied for this. This did not initially receive support from the Commission's Disability Unit at the time. However, a new Head of the Unit, Johan Ten Geuzendan, was supportive of the idea, and eventually a call for the first ANED was launched in 2007. Mark Priestley had been connecting with academics working on disability from a human rights perspective across the EU over the previous years, and, following the publication of the call, many academics travelled to Leeds to discuss submitting a proposal. A successful application was subsequently made for what became the first iteration of ANED.

<sup>13</sup> For further reflections on these developments, see M Priestley, 'Why We Need to Work Together in the European Year of Disabled People' (2002) 17(7) *Disability & Society* 845.

As a result, since 2007, the Commission's Disability Unit has been supported by successive pan-European networks of academics and experts working on disability. This work was initially carried out by ANED and, since 2020, has been carried out by EDE. The network involves a small team of core/senior researchers and at least one academic or, occasionally, an individual researcher, from each Member State and three states in the European Economic Area (EEA) (Iceland, Liechtenstein and Norway). In the past, some of the countries that have association agreements with the EU (Montenegro, Republic of North Macedonia, Serbia, and Turkey),<sup>14</sup> as well as the United Kingdom,<sup>15</sup> have also been covered by the network. As of 2024, EDE covers the 27 EU Member States and Iceland, Liechtenstein and Norway. In many cases, teams of academic researchers based at a specific university carry out work for the network. In this way, the network has also supported the development of academic expertise on disability at the national level. Academics within the network come from a number of different disciplines including law, sociology, politics, education and the broad area of disability studies. The network also involves EDF and Age Platform Europe in carrying out its work, and representatives of these two bodies collaborate with the team of senior researchers.

The current core research team includes, Stefanos Grammenos of the Centre for European Social and Economic Policy; Professor Tamás Gyulavári of the Pázmány Péter Catholic University, Budapest; Professor Paula Pinto of the University of Lisbon; and myself. Until Brexit (2020), Professor Mark Priestley of the Centre of Disability Studies at Leeds University was the scientific director of the network. Other academics who have been members of the core research team in the past include Professor Anna Lawson of Leeds University and Professor Rannveig Traustadóttir of the University of Iceland. Whilst the Commission issues tenders for the managing of the network every three to four years, the same consortium has run the network since its inception, although the individual academics involved has not remained the same.

The network has, amongst other things, provided the Commission with research and evidence to support the implementation of the European Disability Strategies (2010-2020 and 2021-2030) and the CRPD. The network also works on thematic reports every year. This thematic work results in a set of country reports on the specific theme, a report including relevant statistical data, and a synthesis report, which draws on the individual country reports, and includes recommendations, including regarding new policy and legislation, which are directed at various stakeholders, including the Commission. The country reports are based on a template or questionnaire designed by members of the core research team and approved by the Commission. While the core research team suggests themes for these reports, the decision on what to work on is made by the Commission,

<sup>14</sup> Academics from these additional states were only involved in ANED in the second and third funding periods.

<sup>15</sup> Academics from the United Kingdom who reported on the United Kingdom in country reports were involved in ANED until the first funding period after Brexit.

based on its own priorities at the time. For example, following the launch of the European Pillar of Social Rights (Pillar), ANED produced a report that explored how disability rights could be mainstreamed when taking action within the framework of the Pillar,<sup>16</sup> as well as country reports<sup>17</sup> and EU-wide quantitative indicators that relate to persons with disabilities regarding areas covered by the Pillar.<sup>18</sup> Reports addressing an inclusive labour market, the impact of COVID-19, digitalisation and digital transformation, living independently and being included in the community, as well as work on the European Semester were produced during the last EDE contract (2020-2023).

The work of ANED and EDE has impacted on policy-makers in a number of respects. For example, the Commission requested ANED's advice and research to inform its preparation of the European Disability Strategy 2010-2020,<sup>19</sup> and the Commission Staff Working Document that accompanies the Commission's Communication on the Strategy<sup>20</sup> contains 29 references to ANED's work. The aforementioned ANED report on the Pillar is referred to in the latest European Disability Strategy – Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030<sup>21</sup> – to evidence that the quality of disability-related services to support independent living provided across and within Member States varies. This finding helped to justify a flagship initiative that involved the development of a specific framework for Social Services of Excellence for persons with disabilities and improving service delivery for persons with disabilities.<sup>22</sup> Four further references to ANED's work were contained in the Strategy.

The networks' work, and particularly the thematic reports, has also been drawn on in the development of key legislative initiatives, not least of all the European Accessibility Act. The Commission Staff Working Document presenting the Impact Assessment which contains a justification for the decision to propose the Act contains 21 references to ANED's research.<sup>23</sup> This research provided evidence

<sup>16</sup> ANED (edited by L Waddington and M Priestley), 'Mainstreaming Disability Rights in the European Pillar of Social Rights – a compendium' (2018) available at <<https://www.disability-europe.net/search?searchword=Mainstreaming%20Disability%20Rights%20in%20the%20European%20Pillar%20of%20Social%20Rights%20%E2%80%93%20a%20compendium&searchphrase=all>>.

<sup>17</sup> See general and focused country reports via ANED, 'Social Protection – Article 28 CRPD' available at <<https://www.disability-europe.net/theme/social-protection?page=2>> and <<https://www.disability-europe.net/theme/social-protection?page=3>>.

<sup>18</sup> ANED, 'Statistical Indicators – Article 31 CRPD' available at <<https://www.disability-europe.net/theme/statistical-indicators>>.

<sup>19</sup> Commission, 'European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe' COM(2010) 636 final.

<sup>20</sup> Commission, 'Commission Staff Working Document accompanying the Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe COM(2010) 636 final' SEC(2010) 1323 final.

<sup>21</sup> Commission, 'Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030' COM(2021) 101 final.

<sup>22</sup> *Ibid* 8-9.

<sup>23</sup> Commission, 'Commission Staff Working Document, Impact Assessment, Accompanying the document Proposal for a Directive of the European Parliament and of the Council on the approximation of the laws, regulations and administrative provisions of the Member States as regards the accessibility

of how differences in national legal requirements and practices, including on accessibility, constituted a barrier to cross-border trade.<sup>24</sup> In addition the ANED report on *Disability Benefits and Entitlements in European Countries: Mutual Recognition and Exportability of Benefits*,<sup>25</sup> fed into the Commission's work,<sup>26</sup> which resulted in the proposal for a European Disability Card, which was adopted in October 2024.<sup>27</sup>

Network members have also presented findings of the thematic reports at meetings organised by the European institutions. For example, Mark Priestley presented ANED findings on employment and social inclusion at the European Day of Persons with Disabilities and to the European Economic and Social Committee in 2009, while I presented EDE's findings on digitalisation and EU policy at an event organised by MEPs and EDF in 2022.

In addition, ANED and EDE have carried out a number of other important tasks that feed into policy formulation and monitoring. Since the inception of the network, Stefanos Grammenos has had the task of compiling disability-related statistical data using raw material provided by Eurostat. ANED also developed and established the dot.com tool, which provides information on policy and legislation, in terms of action taken to implement the CRPD, across nine broad areas. It covers the obligations set out in the CRPD, as well as relevant legislation and policy in the thirty states covered by EDE.<sup>28</sup> The networks' work has also been used by the Commission to help it to mainstream disability equality in the European Semester process, including the use of annual Country Reports and the recommendations the Commission issues to Member States.<sup>29</sup> The network also

requirements for products and services' SWD(2015) 264 final. Bruno De Witte has noted that there are 'numerous references to academic work and impact assessment reports that accompany new proposals for EU legislation'. De Witte (n 8) IX.

<sup>24</sup> The relevant ANED reports were M Priestley, 'National Accessibility Requirements and Standards for Products and Services in the European Single Market: Overview and Examples' (2013) and A Lawson, 'Maximising the Impact and Effectiveness of Accessibility Measures for Goods and Services: Learning from National Experience, Synthesis Report for the Academic Network of European Disability Experts' (2013) available at <<https://ec.europa.eu/social/main.jsp?catId=1540&langId=en>>.

<sup>25</sup> L Waddington, 'Disability Benefits and Entitlements in European Countries: Mutual Recognition and Exportability of Benefits. A synthesis of evidence provided by ANED country reports and additional sources' (ANED 2010) available at <<https://www.disability-europe.net/downloads/76-aned-2010-task-7-disability-benefits-and-entitlements-report-final-2>>.

<sup>26</sup> The report 'Disability Benefits and Entitlements in European Countries: Mutual Recognition and Exportability of Benefits' was referred to when documenting the work that had been undertaken to fulfil a key action of studying the implications of a mutual recognition of disability cards and related entitlements identified in the European Disability Strategy 2010-2020. Commission, 'Staff Working Document, Progress Report on the implementation of the European Disability Strategy (2010-2020)' SWD(2017) 29 final 56. Twenty further references to ANED were made in this report.

<sup>27</sup> Directive (EU) 2024/2841 of the European Parliament and of the Council of 23 October 2024 establishing the European Disability Card and the European Parking Card for persons with disabilities [2024] OJ L2024/2841.

<sup>28</sup> Commission, 'About DOTCOM – The Disability Online Tool of the Commission' available at <<https://ec.europa.eu/social/main.jsp?catId=1541&langId=en>>.

<sup>29</sup> M Priestley, 'European Semester 2022 Mainstreaming Disability Equality' (European Commission 2022) and the related country reports prepared by EDE available at <<https://ec.europa.eu/social/main.jsp?catId=1532&langId=en>>.

produces an annotated review of EU law and policy that refers to disability.<sup>30</sup> The review provides a mechanism for monitoring and evaluating EU laws and policies that affect persons with disabilities. It contains summaries and details of laws and policies, and has been updated on a (quasi-)annual basis since 2008. The review has been drawn on by the Commission when reporting to the CRPD Committee on the action taken to implement the CRPD.<sup>31</sup>

It is important to emphasise that the Commission decides on the focus of the work of the network. It does this both by setting out general obligations and expectations in the tenders, which are launched every 3 or 4 years, and by liaising with the team of core researchers when agreeing on the annual work programme and individual tasks. This includes choosing topics for the two or three thematic reports that are written every year by the network. These decisions are made based on the Commission's priorities, including in the context of actions planned in the European Disability Strategy and upcoming legislative proposals. In this way, the work of the network feeds directly into the policy needs of the Commission and is carried out with a view to providing input and relevant information for upcoming legislative proposals. On occasion, this has also resulted in innovative research in fields that have not been the subject of significant analysis in the past, such as the work on how disability assessment is carried out.<sup>32</sup> ANED's work has also provided some of the deliverables listed under the Strategies.<sup>33</sup>

While the reports produced by ANED and EDE are generally published online, they remain the property of the Commission, and the Commission is not under any obligation to publish. The networks are described as independent,<sup>34</sup> but the work involves providing the Commission with services, and the Commission must approve all reports, and usually requests further information and makes comments on the first draft of the reports that it receives. Comments that could be interpreted as being critical of the EU, the Commission or Member States, must be supported by solid evidence. However, the Commission has also given permission for research carried out by members of the network to be developed and published in peer-reviewed journals, subject to the proviso that reference is made to the

<sup>30</sup> ANED, 'EU law and policy' available at <<https://www.disability-europe.net/theme/eu-law-and-policy>>.

<sup>31</sup> Commission, 'Initial report of States parties due in 2012 European Union' (3 December 2014) CRPD/C/EU/1 point 204.

<sup>32</sup> The relevant synthesis report for this topic is L Waddington, with contributions from M Priestley and R Sainsbury, 'Disability Assessment in European States, 2018' (ANED 2018). In addition, individual country reports were also written on this topic and are available at <<https://www.disability-europe.net/country>>.

<sup>33</sup> Commission, 'Catalogue of positive actions to encourage the hiring of persons with disabilities and combating stereotypes' (Publications Office of the European Union 2023) available at <<https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8570&furtherPubs=yes>>.

<sup>34</sup> 'The aim of EDE is to collect, analyse and provide independent scientific data and information relating to national policies and legislation, linked with provisions at EU level, as well as providing information about the situation of persons with disabilities'. Commission, 'European Disability Expertise' available at <<https://ec.europa.eu/social/main.jsp?catId=1532&langId=en>>.

funding provided from the Commission for the original research and the inclusion of statements that the views expressed are those of the authors.<sup>35</sup>

Lastly, it is worth considering what the move from ANED to EDE signifies, since it involved more than simply a change of name. ANED was funded under the PROGRESS fund, which was generally used to fund individual projects and studies. ANED existed independently of the Commission and had its own website on which it published reports, following approval of the Commission. The reports were not published by the Commission, and, in that way, there was some distance between the work of ANED and the position of the Commission. As the reports of ANED began to attract more attention from Member States, which were concerned about critical findings, and OPDs, which quoted from ANED findings in their campaigning work, the Commission began to pay greater attention to ensuring the quality of the reports. This can be seen as reflecting the growing impact and significance of ANED's work. With the move from ANED to EDE, the Commission has taken the work of the network 'in house', and the EDE homepage is now found on the website of the Commission and the reports are officially published by the Commission.<sup>36</sup> The required approval for EDE reports – both in terms of acceptance by the Commission and regarding the decision to publish – now involves Commission officials at a more senior level than was the case under ANED. Moreover, the use of the network's work by the Commission is increasing. The move from ANED to EDE therefore arguably reflects the greater impact on European policy-makers that the network is having, and its work is certainly viewed in a more serious light than when ANED was initially established.<sup>37</sup>

## 4. Academics and Other EU Institutions

### 4.1. The Role of Academics in Policy Formulations

Academics also collaborate with other EU institutions in policy formulation. For example, I and other academics have worked with individual MEPs, such as Richard Howitt<sup>38</sup> and Kathalijne Buitenweg,<sup>39</sup> to help draft amendments to legislative

<sup>35</sup> M Priestley *et al.*, 'The political participation of disabled people in Europe: rights, accessibility and representation' (2016) 42 *Electoral Studies* 1–9; L Waddington and M Priestley, 'A human rights approach to disability assessment' (2020) 37(1) *Journal of International and Comparative Social Policy* 1–15; M Priestley and S Grammenos, 'How useful are equality indicators? The expressive function of 'stat imperfecta' in disability rights advocacy' (2021) 17(2) *Evidence & Policy* 209–226.

<sup>36</sup> Commission (n 34).

<sup>37</sup> I am grateful to Mark Priestley for discussing the significance of the move from ANED to EDE with me.

<sup>38</sup> Richard Howitt was a British MEP representing the Labour Party from 1994 until 2016 and was Chair of the Disability Intergroup.

<sup>39</sup> Katalijne Buitenweg was a Dutch MEP representing Green-Left from 1999–2003 and rapporteur for the Committee on Civil Liberties, Justice and Home Affairs on the proposal for a Council directive on implementing the principle of equal treatment between persons irrespective of religion or belief,

proposals that address disability equality. A further route for Parliamentarians to draw on academic expertise is through the Disability Intergroup, which brings together MEPs who have an interest in disability,<sup>40</sup> and I have spoken at events organised by the Intergroup in the past. In addition, the Petitions Committee of the EP commissions an annual study (or report) on a disability-related issue that is relevant to their work, as well as holding an annual workshop on the rights of persons with disabilities, at which the issue and related study is discussed with MEPs, as well as representatives from other key EU institutions, such as the Ombudsman and the Disability Unit of the Commission. The Committee established this practice after receiving the recommendation that it continue to hold dedicated hearings to promote disability issues in the first full study which it commissioned. That study concerned the implementation of the CRPD and was written by Mark Priestley, Meredith Raley and Gauthier de Beco.<sup>41</sup> The topics and studies covered since 2020 are the post-2020 European Disability Strategy,<sup>42</sup> the implementation of the 2015 Concluding Observations of the CRPD Committee by the EU,<sup>43</sup> Disability Assessment, Mutual Recognition and the EU Disability Card,<sup>44</sup> and Coping with the Cost-of-Living Crisis.<sup>45</sup>

Academics are also sometimes asked to speak on disability-related issues at events organised by other European institutions, such as the European Economic and Social Committee and the European Committee of the Regions.<sup>46</sup> In addition, Member States that hold the Presidency of the Council regularly organise meetings and conferences on disability as part of their work, and I and other academics have often spoken at these policy forum events.

I am also aware of at least one disability-related case in which a judge at the CJEU spoke to an academic in person before deciding on how to rule in the case. Aside from such anecdotal evidence, there is no way of knowing how often such

disability, age or sexual orientation in 2008. The report proposed amendments to the Commission's proposal. European Parliament, 'Report on the proposal for a Council directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation' P6\_TA(2009)0211.

<sup>40</sup> EDF, 'Disability Intergroup' available at <<https://www.edf-feph.org/disability-intergroup/>>.

<sup>41</sup> M Priestley, M Raley and G de Beco, 'The Protection Role of the Committee on Petitions in the Context of the Implementation of the UN Convention on the Rights of Persons with Disabilities' Study for the PETI Committee, Policy Department Citizens' Rights and Constitutional Affairs (European Parliament 2016).

<sup>42</sup> L Waddington and A Broderick, 'The Post 2020 European Disability Strategy' Study for the PETI Committee, Policy Department Citizens' Rights and Constitutional Affairs (European Parliament 2020).

<sup>43</sup> JC Smits, 'The Implementation of the 2015 Concluding Observations of the CRPD Committee by the EU' Study for the PETI Committee, Policy Department Citizens' Rights and Constitutional Affairs (European Parliament 2021).

<sup>44</sup> M Priestley, 'Disability Assessment, Mutual Recognition and the EU Disability Card, Progress and Opportunities' Study for the PETI Committee, Policy Department Citizens' Rights and Constitutional Affairs (European Parliament 2022).

<sup>45</sup> M Birthi, E Zólyomi, F Wohlgemuth and S Gjylsheni, 'Targeted measures for persons with disabilities to cope with the cost-of-living crisis' Study for the PETI Committee, Policy Department Citizens' Rights and Constitutional Affairs (European Parliament 2023).

<sup>46</sup> This has also been noted by Bruno De Witte. De Witte (n 8) IX.

interactions involving members of the Court and its Advocates General and academics happen, although such references and contacts are arguably all the more likely when academics have already foreseen the specific legal issues that arise in the case, and have addressed it in light of European (and national) legislation and case law in their writing. However, Bruno De Witte argues that the extensive legal knowledge of jurists at the Court 'diminishes the need to reach out for academic input to find solutions for their daily legal problems'.<sup>47</sup>

## 4.2. Academics as Law- and Policy-makers within EU Institutions

In addition to the contribution of academics to the work of the European institutions mentioned above, some academics have moved in and out of employment with the European institutions, or maintained an involvement in academia whilst working for the institutions, and have exerted an influence on EU disability law and policy in this way.<sup>48</sup> For example, Miguel Poiars Maduro, as Advocate General to the CJEU, wrote a very influential Opinion in the case of *Coleman*, which concerned alleged discrimination against a worker on the grounds of her association with her disabled son. The Opinion is notable both for its analysis and reflection on the principles underlying non-discrimination and equality legislation, and for its reference to academic literature. He advised the Court to hold that the directive 'protects people who, although not disabled themselves, suffer direct discrimination and/or harassment ... because they are associated with a disabled person',<sup>49</sup> and the Court followed this approach in its judgment.<sup>50</sup> Miguel Poiars Maduro has held a number of academic and political appointments and, following his tenure as Advocate General, he became the director of the School of Transnational Governance and professor of law at the European University Institute, and continues to be a part-time professor at the School.<sup>51</sup> Another example of an employee of the EU institutions who has maintained academic links is Álvaro Oliveira who has worked on equality issues, including, at times, disability issues, at the Commission for many years. Álvaro Oliveira is an active member of the Berkeley Center on Comparative Equality and Anti-Discrimination Law,<sup>52</sup>

<sup>47</sup> Ibid.

<sup>48</sup> Ibid VIII.

<sup>49</sup> Opinion of Advocate General Poiars Maduro delivered on 31 January 2008 in Case C-303/06 *S. Coleman v Attridge Law and Steve Law* ECLI:EU:C:2008:61, para 25.

<sup>50</sup> Case C-303/06 *S. Coleman v Attridge Law and Steve Law* ECLI:EU:C:2008:415. For a discussion of the judgment and the Advocate General's Opinion see L. Waddington, 'Case C-303/06, *S. Coleman v. Attridge Law and Steve Law*, Judgment of the Grand Chamber of the Court of Justice of 17 July 2008' (2009) 46(2) *Common Market Law Review* 665–681.

<sup>51</sup> See 'Luis Poiars Pessoa Maduro' available at <<https://www.eui.eu/people?id=luis-poiars-pessoa-maduro>>.

<sup>52</sup> See 'Berkley Center on Comparative Equality and Anti-Discrimination Law' available at <<https://www.law.berkeley.edu/research/berkeley-center-on-comparative-equality-anti-discrimination-law/about-us/membership-list-2/#bb0-last-name-m-r-2/>>.

and has regularly published in academic journals.<sup>53</sup> Lastly, Gerard Quinn, who has made a significant contribution to academic research on disability rights, worked as a temporary civil servant at the European Commission on equality and disability policy in the 1990s. Both Miguel Poiars Maduro and Álvaro Oliveira, as well as myself, studied at the European University Institute in the early 1990s.

## 5. Academics Working with Organisations of Persons with Disabilities, the European Disability Forum and the Disability Movement

OPDs at the European level, including EDF, but also organisations such as the European Network of Independent Living, campaign on important issues that concern, for example, Treaty amendments, proposing new legislation, and amendments to existing legislative proposals. Academics can help OPDs to formulate arguments that can be used to convince policy-makers to support the OPD's position, as well as drafting concrete proposals for legislative amendments.

As discussed by Coveney in this volume, EDF, as the umbrella organisation representing the interests of persons with disabilities in Europe, plays a leading role in coordinating policy work.<sup>54</sup> However, European based OPDs which existed before EDF became an independent organisation in 1996, have also made an important contribution. One of the most important examples of pre-EDF collaboration amongst European level OPDs concerns the *Invisible Citizens* report, and the related discussions and presentations that took place around the European Day of Disabled Persons on 3 December 1995.<sup>55</sup> While today the annual European Day is jointly organised by the Commission and EDF, and, on the whole, does not provide OPDs with a platform for campaigning for new legislation and policy, the event was somewhat different in the 1990s. In those early years of the European Day, the European Commission provided funding for the event, but it was organised wholly by European level OPDs, which had a great deal of freedom in deciding what to address and whom to invite to speak. The event was also not held within a building belonging to the EU institutions, as it is now.

<sup>53</sup> Á Oliveira, M De la Corte-Rodríguez and F Lütz, 'The New Directive on Work-Life Balance: Towards a New Paradigm of Family Care and Equality?' (2020) 45 *European Law Review* 295–323.

<sup>54</sup> C Coveney, 'The Role of the European Disability Forum and Disability Organisations in Shaping EU Disability Policy' in this volume.

<sup>55</sup> For information on the first European Day of Disabled People, which addressed similar issues, see M Priestley, 'We're all Europeans now! The social model of disability and European social policy' in C Barnes and G Mercer (eds), *The Social Model of Disability: Europe and the Majority World* (The Disability Press 2004) 21–23; M Bell and L Waddington, 'The 1996 Intergovernmental Conference and the Prospects of a Non-Discrimination Treaty Article' (1996) 25(4) *Industrial Law Journal* 328; Report of the First European Disabled People's Parliament, 3 December 1993 available at <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/DPI-first-European-Disabled-Peoples-parliament.pdf>>. The article by Bell and Waddington also contains information on the 1995 and 1996 European Days of Disabled Persons at 328.

The 1995 European Day was jointly organised by Autism-Europe, ERC-WFMH (now Mental Health Europe) and ILSMH-European Association (now Inclusion Europe) and focused on the absence, or ‘invisibility’, of persons with disabilities in European Community legislation and, in particular, the Treaty which conferred competence on the EU to act. It addressed the need for a Treaty amendment and secondary legislation addressing disability discrimination as well as certain other issues. It explicitly called for an amendment to the non-discrimination clause in Article 6 of the Treaty on European Union (TEU), so that the relevant article referred to discrimination on the ground of disability, as well as the other ‘invisible’ grounds of race, sexual orientation and religion. Mark Priestley has argued:

Since the campaign prioritised legal recognition, input was increasingly invited from those with legal expertise (particularly human rights lawyers). So, while the impetus arose from the self-advocacy of disabled people’s organisations, grounded in a broadly ‘social’ approach, developments took an increasingly legalistic turn.<sup>56</sup>

A team of legal academics and practicing lawyers, with and without disabilities, made presentations on the status of persons with disabilities under EU law, and the need for Treaty amendments and further legislation to address disability discrimination, and other issues, over the two-day event in Brussels. Real life examples of disability discrimination were presented, and information on non-discrimination legislation adopted by EU Member States, and by States outside Europe, were discussed. There was a lot of interaction with the representatives of European and national OPDs who attended the event. Looking back on the event now, I realise how exciting, innovative and empowering it was. It also provided the basis for the long campaign to ensure the inclusion of a disability non-discrimination provision in the Amsterdam Treaty, which happened in 1997.

The *Invisible Citizens* report linked to the 1995 European Day was published on 7 December,<sup>57</sup> and had, as its sub-title, *Disabled Persons’s Status in the European Treaties*. It had a foreword by Barbara Schmidbauer MEP, who was chair of the Disability Intergroup at the EP, and a preface by Theresia Degener, who was a lecturer and researcher at the Law Faculty of Goethe University Frankfurt at the time. The first chapter, which I wrote, was entitled *Disabled people are invisible in the Treaties – Why the European Treaties should contain a non-discrimination provision*. In a previous draft of the report, the chapter had been entitled *What ‘added value’ would European action have?*, and was the penultimate chapter of the report. The decision to move the chapter and to change its title was based on the fact that this chapter set out the key goal of the disability movement and contained arguments as to why such a Treaty amendment was necessary. It revealed how discrimination led to many persons with disabilities being denied rights associated

<sup>56</sup> Priestley (n 55) 22.

<sup>57</sup> EDF, ‘Disabled Persons’ Status in the European Treaties – Invisible Citizens’ (European Day of Disabled Persons 1995, 7 December 1995) D/1995/7560/2.

with EU citizenship, including rights concerning free movement of persons; freedom to provide services and freedom to establish themselves in business in another Member State; freedom to receive services and freedom to purchase goods; and the right to vote. It also argued that there would be economic and social benefits of a binding European instrument that prohibited disability discrimination. Lastly, it submitted that a directive would be the most appropriate form for a binding disability non-discrimination instrument.<sup>58</sup>

Other chapters in the report covered real life experiences of disability discrimination experienced by people across Europe (by Colin McKay, Legal and Policy Adviser of ENABLE in Scotland); disability discrimination within the European institutions (by Aart Hendriks and myself); disability non-discrimination measures adopted by the Member States (containing brief reports from legal experts in Germany, Finland, France, the United Kingdom, Ireland, Sweden and Portugal); and international human rights instruments and disability anti-discrimination law in the United States, Australia and Canada (by Gerard Quinn and Aart Hendriks). The final chapter, by Horst Frehe (a German judge) and Theresia Degener, was entitled *The Way Forward*, and contained detailed and very specific proposals for Treaty amendments and their justifications. I and other legal experts also contributed to this chapter.

In retrospect, this event, and the *Invisible Citizens* report,<sup>59</sup> laid the ground for a concerted and effective campaign led by OPDs across Europe to secure important amendments to the Treaties at the Amsterdam Inter-Governmental Conference. Following the adoption of the Amsterdam Treaty, EDF, by now an independent organisation, published a *Guide to the Amsterdam Treaty*, which was written by the Legal Rights Working Group that I chaired. Nicola Bedlington, the Director of EDF at the time, contributed a chapter to the Guide that analysed the campaigning work that had been done. That chapter said the following about the 1995 European Day and the *Invisible Citizens* report:

This report played a fundamental role in influencing opinions within the institutions, substantiating arguments in favour of a non-discrimination clause with sound legal analysis. The report moreover acted as a vital awareness-raising tool with disabled people's organisations. It rendered EU policy both accessible and relevant to disabled people across the Union, and put them on the centre stage.<sup>60</sup>

Following the publication of the report, and the establishment of EDF as an independent organisation, myself and other legal academics supported the campaign by providing legal and policy arguments in support of a Treaty amendment. A second report, entitled *How can disabled persons in the European Union achieve equal rights as citizens? The legal and economic implications of a non-discrimination*

<sup>58</sup> The chapter also published in an adapted form as L Waddington, 'The European Community and Disability Discrimination: time to address the deficit of powers?' (1997) 12(3) *Disability & Society* 465–479.

<sup>59</sup> EDF (n 57).

<sup>60</sup> EDF, 'Guide to the Amsterdam Treaty' (EDF, March 1996) Chapter 3 A.2.

clause in the Treaty of the European Union, was written to mark the 1996 European Day of Disabled Persons, which was organised by the same three OPDs as had organised the 1995 event. This report was written by a legal and economic expert working group that I chaired, and which also involved Aart Hendriks, Tom McCarthy and John Wall. The report was structured around 14 questions, such as 'What effect would the proposed non-discrimination clause have at the Community level?'; 'Would a non-discrimination clause breach the principle of subsidiarity?' and 'What would be the economic consequences of the proposed non-discrimination clause?'. The report responded to points raised in the Reflection Group report, which defined the agenda for the Intergovernmental Conference. This report made it clear that the vast majority of Member States favoured amending the Treaty so as to include a non-discrimination clause that referred to disability, although there were some concerns regarding 'any disproportionate economic consequences which might derive from such a provision'.<sup>61</sup> At 23 pages, the 1996 report was considerably shorter than the *Invisible Citizens* Report, which exceeded 100 pages. The 1996 report, and the related European Day, supported the campaign to include a disability non-discrimination clause in the EU Treaty, but was not as groundbreaking as the *Invisible Citizens* report, given that it was far more technical in nature.

The work that needed to be carried out to secure the Treaty amendment was not only addressed to governments within the Member States but also to the national disability councils of the Member States. Ensuring that all national councils were on board was vital, as the Treaty could only be amended with the agreement of all Member States. This meant that each national council had to support such a change.

Whilst almost all national disability councils were supportive of such a Treaty amendment from the start, the Danish National Council was somewhat sceptical. The Danish disability movement had a good and cooperative relationship with the Danish government, and the establishment of mandatory disability non-discrimination provisions was not seen as the 'Danish way'. Instead, there was a preference for mainstreaming disability within law and policy. I travelled to Copenhagen as part of a small EDF delegation with the aim of persuading the Danish National Council to support the inclusion of the non-discrimination clause in the Treaty, or at least not to oppose it. This was a friendly meeting at which Danish representatives asked pertinent questions. Ultimately, while the National Council were not convinced of the value of such a clause for people with disabilities in Denmark, they decided to adopt a neutral stance towards their government representatives, and they did not oppose the inclusion of the clause. This was very important for the overall campaign.

<sup>61</sup> Reflection Group's Report (Messina 2 June 1995, Brussels 5 December 1995) available at <[https://www.europarl.europa.eu/enlargement/cu/agreements/pdf/reflex1\\_en.pdf](https://www.europarl.europa.eu/enlargement/cu/agreements/pdf/reflex1_en.pdf)> para 39. Bell and Waddington (n 55) 328.

A further important element of the campaign was the support for national disability councils and staff of OPDs in Brussels to lobby on the Treaty amendment. I collaborated with colleagues in European level OPDs and the Disability Intergroup in the EP to provide training and advice on how to lobby at the national level. Diana Sutton, who was based in Barbara Schmidbauer's Office at the Parliament, and who was the coordinator of the Intergroup, played a key role in organising this training.

One such training took place in Brussels in the first half of 1996. We drafted a quiz that was intended to stimulate discussion between participants, rather than to test knowledge. Examples of questions included in quiz are:

Which of the following groups are specifically mentioned in the EU Treaty (including in declarations and protocols)?

- a) Animals
- b) Disabled people
- c) Workers
- d) Fish
- e) Women

(Answer – all mentioned, except for disabled people)

Another example is:

What is the view of the following Member States on a non-discrimination clause on the ground of disability?

- a) UK – for – against – considering it
- b) Ireland – for – against – considering it
- c) Greece – for – against – considering it
- d) Italy – for – against – considering it

(Answer: UK – against; Ireland – for; Greece – for; Italy – for)

The training also involved a role-playing session in which I and some colleagues from European level OPDs took on the role of sceptical government ministers or civil servants, and representatives of the national OPDs made arguments to convince us to support the Treaty amendment. We provided participants with lobbying tips and the lobbying drew on the reports produced for the European Day events in 1995 and 1996.

In April 1997, shortly before the Inter-Governmental Conference in Amsterdam at which the new Treaty was agreed on, I was part of an EDF delegation that met Michiel Patijn, the Dutch Secretary of State for Europe. We discussed the need for a non-discrimination clause and a number of other provisions in the new Treaty. Securing the support of the Netherlands was vital, as that country held the Presidency of the Council. Other members of the EDF delegation talked about the importance of prohibiting disability discrimination and the need to ensure persons with disabilities were recognised in the Treaties. The minister listened politely but did not really engage with us. I was the last to speak, and presented legal arguments in favour of including a non-discrimination clause in the Treaty,

noting how this would extend rights that other EU citizens already had to persons with disabilities. I also discussed the need to include a reference to disability in the internal market provision (Article 100a TEC at the time). The minister, who had a legal training, asked me a number of questions and made sure his assistant made more detailed notes on this part of the discussion. We were successful in making our case in that the minister agreed that EU legislation setting common standards for goods can fail to take into account the needs of consumers with a disability, and he welcomed arguments that favoured including a reference to disability in Article 100a TEC. In fact, the Amsterdam Treaty did not make a disability-related amendment to the internal market provision, which was renumbered Article 95 TEC, but it did insert a non-binding declaration that read:

The Conference agrees that, in drawing up measures under Article 95 of the Treaty establishing the European Community, the institutions of the Community shall take account of the needs of persons with a disability.

This wording mirrored the proposal that I had drafted for EDF, and which the disability movement had campaigned on.

As is well known, the Amsterdam Treaty also resulted in the inclusion of a non-discrimination clause, in what is now Article 19 TFEU, which provides the EU with the power to adopt legislation to combat discrimination on a variety of grounds, including disability. This led to the adoption in 2000 of the Employment Equality Directive, which prohibited disability discrimination in the field of employment and vocational training, as well as addressing discrimination on the grounds of religion or belief, sexual orientation and age.<sup>62</sup>

In the aftermath of the Amsterdam Treaty and the adoption of the Employment Equality Directive, I continued to have a close relationship with EDF and, at the end of 2004, EDF and Maastricht University collaborated to establish the Chair in European Disability Law to which I was appointed. In the years that followed, I worked closely with EDF, giving oral and written advice and input into policy documents, and often speaking at Board Meetings and Annual General Meetings. EDF secured funding for a capacity building project in the ten new Member States that joined the EU in 2004, and, along with a team involving EDF staff and representatives of EDF member organisations, I spoke at several national seminars which introduced representatives of OPDs in the new Member States to the EU, and EU disability law and policy in particular, and the work of EDF and its members. Between 2003 and 2006, I also coordinated Maastricht's involvement in a project funded by the European Commission to train disability activists in European and national non-discrimination law in

<sup>62</sup> A more in-depth discussion of both the *Invisible Citizens* campaign and the *1Million4Disability* campaigns is provided in C Coveney, 'A History of European Disability Campaigns: Civil society, social movements & opportunities for counterhegemonic change' (2023) Ph.D. thesis, University of Leeds (on file with author). See also C Coveney, 'The Role of the European Disability Forum and Disability Organisations in Shaping EU Disability Policy' in this volume.

which EDF members participated,<sup>63</sup> and a week's training for activists from EDF member organisations was held in Maastricht at the end of March 2004.

However, perhaps the biggest project I was involved in with EDF during this period was drafting a proposal for a directive to combat disability discrimination in fields beyond employment. As noted above, following the coming into force of the Amsterdam Treaty, the EU adopted the Employment Equality Directive. A second directive, the Racial Equality Directive, had also been adopted in the same year, and this had a broader material scope that covered social protection, including social security and healthcare, social advantages, education, and access to goods and services including housing, as well as employment and vocational training.<sup>64</sup> A similarly broad material scope applied to the legislation prohibiting discrimination on the basis of sex/gender. Civil society organisations that represented groups which were covered by the Employment Equality Directive urgently wanted the Commission to propose a new directive, which would extend the material scope of the protection from discrimination for the groups they represented to that found in the Racial Equality Directive. However, the Commission resisted this on the ground that the Member States needed time to transpose the 2000 directives.<sup>65</sup>

In an attempt to put pressure on the Commission to propose a new equality directive that specifically prohibited disability discrimination, EDF launched the 1Million4Disability campaign to collect a million signatures to a petition that called on the Commission to make such a proposal.<sup>66</sup> In doing so, EDF made use of the 'European Citizen's Initiative'<sup>67</sup> established in the Maastricht Treaty.<sup>68</sup> Alongside this initiative, I drafted a proposal for the directive that EDF wanted the Commission to propose, and which EDF intended to present to the institution. This work was done in close consultation with EDF members and the EDF Board. It was a tricky exercise because I had to balance the expectations of EDF members with what the EU was actually able to adopt based on the competences provided for in the Treaties. In that sense, the process was also a capacity building exercise for EDF, in that it involved detailed discussions of EU legal competences and reflections on how to address the legitimate aspirations of EDF members. I worked on the proposal for more than 12 months. In 2007, the proposed directive was submitted to the Commission.<sup>69</sup> As is now well known, in 2008 the Commission

<sup>63</sup> The project was funded under the EC Non-Discrimination Action Programme.

<sup>64</sup> Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin [2000] OJ L180/22.

<sup>65</sup> L Waddington, 'A Disabled Market: Free Movement of Goods and Services in the EU and Disability Accessibility' (2009) 15(5) *European Law Journal* 575–598.

<sup>66</sup> M Priestley, 'In Search of European Disability Policy: Between National and Global' (2007) 1 *Alter Revue européenne de recherche sur le handicap* 67.

<sup>67</sup> Article 11(4) of the Treaty on European Union (TEU) establishes the basic framework for that right, and Article 24(1) of the Treaty on the Functioning of the European Union (TFEU) sets out the general principles for a regulation defining concrete procedures and detailed conditions.

<sup>68</sup> A Davoli, 'European Citizens' Initiative – Factsheet' (European Parliament, October 2023) available at <<https://www.europarl.europa.eu/factsheets/en/sheet/149/european-citizens-initiative>>.

<sup>69</sup> Coveney (n 61).

did propose a Horizontal Equality Directive, covering disability and the other grounds addressed in the Employment Equality Directive, which went beyond material scope of the latter Directive.<sup>70</sup> There is no evidence that the disability-specific document I drafted for EDF influenced the Commission's proposal. To date, that proposal remains stalled in the Council, and it is currently the legislative proposal, which has remained unadopted for the longest period of time without being withdrawn. EDF continues to advocate for its adoption, although this no longer has the priority which it once had.

EDF's collaboration with academics has changed over the years. In the first decade or so following its establishment as an independent organisation (up until 2006 approximately), EDF worked with a Legal Rights Working Group, which was made up of academics and other individuals with a legal background, such as practitioners. I chaired the Working Group and other members included, at various times, Aart Hendriks (at the time a lecturer in health law at the University of Amsterdam, and now Professor at the University of Leiden), Gerard Quinn (at the time Director of Research at the Irish Law Reform Commission and now Emeritus Professor at the University of Galway) and Shivaun Quinlivan (University of Galway). Other members, who worked as practitioners, included the late Sir John Wall (judge in the UK), Helga Stevens (who later became a MEP) and Angel Ballesteros (a consultant from Spain). The Legal Rights Working Group gave EDF advice on issues relevant to campaigning and, in the first years of EDF, produced policy documents and reports/papers to support campaigns. For example, following the adoption of the Amsterdam Treaty, members of the Legal Rights Working Group wrote a 50 page guide to the new Treaty from a disability perspective.<sup>71</sup> This reflected the dual role of the Legal Rights Working Group, which involved both support for influencing policy, as well as capacity building for EDF members.

EDF now works with academics to a lesser degree than in the past. Arguably this is partly the result of having an expanded in-house staff who have diverse expertise, and because it carries out a lot of work through various committees, which are made up of representatives of its member organisations. At times, it works with legal practitioners who offer their services on a pro bono basis. Occasionally, EDF puts out a small tender for a report and related presentation on a specific topic which relates to its campaigning work, and academics are sometimes awarded these. In 2021, for example, I wrote, on a pro bono basis, a report for EDF on the prohibition of disability discrimination with regard to healthcare in the EU.<sup>72</sup> EDF also collaborates with academics in research projects funded by the European Commission and receives so many invitations for such

<sup>70</sup> Commission, 'Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation' COM(2008) 426 final.

<sup>71</sup> See Independent Living Institute, 'Guide to the Amsterdam Treaty' available at <<https://www.independentliving.org/docs3/edf98.html>>.

<sup>72</sup> EDF, 'Our Work on Health Policy' available at <<https://www.edf-feph.org/health-policy/>>.

collaborations that it has to prioritise and be selective in deciding which partnerships to work with. Many of EDF's members also collaborate with academic teams on such projects to co-produce research which can be of relevance to European policy makers amongst others.

## 6. Academics and Research Projects Funded by the EU

The EU funds a substantial amount of academic and applied research through its multi-year flagship research funds. The current programme, Horizon Europe, covers the period 2021-2027. Its most recent predecessors were the 7th Framework Programme for Research (FP7) (2007-2013) and Horizon 2020 (2014-2020). While much of the funded research that explicitly addresses the situation of persons with disabilities is medically or technologically oriented, the programmes have also sometimes funded research that embraces a rights-based approach to persons with disabilities.

The calls for tender under these programmes are often rather broad and, unlike ANED and EDE service contracts mentioned above, researchers have a substantial amount of freedom in developing and implementing the projects. In some cases, the calls for tender that result in disability-related research being funded may explicitly focus on persons with disabilities; however, a reference to persons with disabilities may only be made in passing in the call, or no reference may be made at all. Nevertheless, such calls can still result in the funding of research projects that explicitly include a disability dimension. Exerting direct influence on EU law is unlikely to be an explicit goal or 'deliverable' of a funded project. However, projects may influence EU law or policy in some ways in the long term, for example by training individuals who go on to work for the EU institutions or producing academic research which influences policy makers.

I have been involved in two Marie Skłodowska-Curie doctoral training networks that involved EU funding for networks of Early-Stage Researchers (ESRs)/PhD researchers working on disability-related research. Both the Disability Rights Expanding Accessible Markets (DREAM) and the Disability Advocacy Research in Europe (DARE) training networks were coordinated by the University of Galway in Ireland, and the two networks trained almost thirty ESRs in total. The ESRs have gone on to hold academic positions within and outside Europe, to work for civil society organisations in the field of disability, and to work for consultancy organisations based in Brussels. As far as I am aware, none of the ESRs who received training via DREAM or DARE have gone on to work for European institutions or national governments of the Member States, although some of them have collaborated with ANED, EDE and the Network on Gender Equality and Non-Discrimination law.

Another relevant EU-funded research project is European Research Agendas for Disability Equality (EuRADE), which was funded under FP7, and which ran

across 2008 and 2009.<sup>73</sup> The project was coordinated by EDF, while Maastricht University and Leeds University were partners. Myself and Mark Priestley were academic Principal Investigators (PIs) on the project. The project built the capacity of European OPDs to participate in the FP7 research programme and other relevant research initiatives. It also enabled EDF and its member organisations to identify and articulate the research priorities of OPDs; provided research knowledge and skills to OPDs; and identified opportunities for larger scale collaboration between OPDs and European research partners in priority areas.

While EuRADE did not aim to influence EU law directly, it did seek to influence the EU policy-makers who determined the priorities for EU funded research, and to ensure greater funding for disability-related research in future calls under FP7. The EuRADE team and participating OPDs gave briefings on the research priorities of persons with disabilities and how disability could be mainstreamed more effectively into EU calls. One briefing was hosted by the European Parliament in Brussels in 2009, and involved contributions from MEPs and European Commission officials who were responsible for FP7 calls in Social Science, and Science in Society, as well as Eurostat. The EuRADE team also published recommendations to the European Commission on how to align EU research and development funding with the social model and human rights-based approach to disability, and how to promote greater participation by OPDs in research. Following the conclusion of EuRADE, the FP7 Social Sciences and Humanities work programme included a call for a disability specific research project based on the social model of disability, which involved funding of 2.5 million euros.

The project that was funded as a result of this disability specific call was 'DISCIT – Making persons with disabilities full citizens'. It was coordinated by Professor Bjørn Hvinden, Bettina Uhrig and Rune Halvorsen of the Norwegian Social Research (NOVA), which was an institute at Oslo and Akershus University College of Applied Sciences. I was a member of the Advisory Board and an expert consultant on the project. The project ran from 2013 until 2016, and involved ten organisations, including six universities, two research institutes and two civil society organisations. It provided new knowledge about disability policies in European countries and identified the actions policy-makers and stakeholders needed to take to enable persons with disabilities to exercise active citizenship and participate fully in society on an equal basis with others. Its work resulted in eight Policy Briefings.<sup>74</sup> While the researchers behind DISCIT carried out research on the project's impact on policy-makers at the end of the project, they found that it was too soon for the project to have had an effective and wide impact on European policies. This research was based on interviews with researchers involved in the

<sup>73</sup> Commission, 'European Research Agendas for Disability Equality – EURADE' available at <<https://cordis.europa.eu/project/id/217783/en>>.

<sup>74</sup> See DISCIT Final Report – Executive Summary (Oslo, 20 April 2016) available at <<https://oda.oslomet.no/oda-xmli/bitstream/handle/20.500.12199/6499/DISCIT-Final-Report-Executive-Summary-April-2016.pdf?sequence=1&isAllowed=y>>.

project. However, they did note that some of the members of the research team had been invited to be part of the High-Level Group on Disability, a committee made up of European and national experts that helped to define the strategies for implementing the CRPD in Europe. They also found that achieving (quick) policy impact required support measures, for example documents based on research findings that are immediately intelligible to policy-makers.

## 7. Concluding Remarks

The past 30 years has seen the emergence of a cohort of academic researchers working on European disability law and policy. These researchers work in a variety of disciplines and across different European states. This has been stimulated by the development of EU disability law and policy, which has provided the 'subject' for such researchers to work on, as well as by the availability of EU funding, which supports disability-related research. The pan-European academic research network EDE, and its predecessor ANED, have come to play an increasingly important role in the development of EU disability policy, and this is reflected by the Commission taking 'in house' EDE research outputs, which are now published on the Commission's homepage, and the more critical assessment and closer monitoring of EDE's research outputs by the Commission. Moreover, EDE is now used to provide some of the deliverables related to the European Disability Strategy, as well as laying the ground work for some of the European Commission's initiatives and contributing to the EU's reporting process to the CRPD Committee.

At the same time, a wide-ranging and highly professional set of organisations that represent the interests of persons with disabilities, at both a national and European level, has emerged. These parallel developments have facilitated research collaborations in which academics and representatives of OPDs have co-produced research through projects funded through the European Commission and, in some cases, this research has concerned policy issues. Moreover, in the past European OPDs have worked closely with, in particular, legal academics to develop arguments to support lobbying in favour of Treaty amendments and secondary legislation that recognises the rights of persons with disabilities including, significantly, the right to equality and non-discrimination. This has proved a powerful combination, which reached its highpoint in the 1990s during the successful campaign to secure the inclusion of a non-discrimination clause addressing disability in the Amsterdam Treaty. Collaboration between European OPDs and academics in terms of campaigning and lobbying has declined since then as OPDs have acquired more expertise in-house. However, there remains an open dialogue between researchers and OPDs, particularly in terms of collaboration on research projects.

