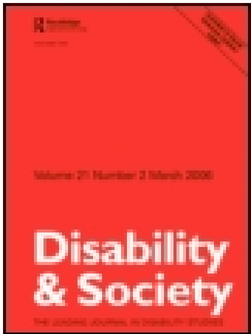

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Politically disabled: barriers and facilitating factors affecting people with disabilities in political life within the European Union

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ABSTRACT

Diversity is a current buzzword in politics, but in the EU, people with disabilities are not achieving the gains made by women and ethnic minorities. This research examined barriers and facilitating factors through a literature review and interviews with politicians and political activists in five European countries. Six categories of barriers and facilitating factors were found: networks, recruitment and mentoring, resources (money, time and energy), the "hierarchy of impairments," accessibility of political spaces and activities, and laws and policies. Key recommendations include removing access barriers to political participation, from voting to holding office, including physical and procedural barriers in political spaces; ensuring that equalities legislation covers politicians; eliminating barriers imposed by benefits systems; promoting direct support for political activists, candidates and office-holders with disabilities, including access to necessary services and supports; encouraging parties to recruit and mentor disabled people with leadership potential; and considering quotas and job-sharing.

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Politics; politicians with disabilities; activism; inclusion

Points of interest

- Not many disabled people are active in politics. In the EU, about 15% of people have an impairment, but only around 1% of politicians do.
- Inclusion at school and in social groups makes it easier to get into political jobs or to try to get elected.

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- Some disabled political activists, volunteers, candidates and office-holders don't get the support they need.
- Political parties can help by finding disabled people, supporting them, and helping them get involved in politics.
- Our article provides several ideas about how to make it easier for disabled people to run for office and work in politics.

Introduction

Modern Europe is diverse. Europeans have struggled to reflect this in their national legislatures and ministries, and in the European Parliament and other EU institutions. Representation of women and ethnic minorities in government is recognised as important, and measurable strides have been made throughout the EU over the past 40 years. However, approximately 15 percent of people living in Europe have an impairment (World Health Organisation 2011). Political interest and talent can come in many different packages, so it stands to reason that citizens who seek to represent their neighbourhoods, cities, regions and nations should reflect diversity in terms of physical and mental shape and ability as well.

In 2018, the Secretariat of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities released an official 'Note' regarding participation of disabled people in political and public life (CRPD/CSP 2018), which was further discussed by member groups via the CRPD Conference. In keeping with the majority of research and action on political participation (e.g. Savery 2015; Belt 2016; OSCE/ODIHR 2017; Willis et al. 2016), this policy document focused primarily on basic levels of political participation: the right to vote and express political views. Other forms of political participation include membership of a political party; forming or participating in civil society organisations such as unions; and political activism (Skelton and Valentine 2003; Campbell and Oliver 1996; OSCE/ODIHR 2017). While some barriers to political participation are well-known (see, for example, Schur 1998), facilitating factors are not as well-defined, and so are harder to replicate. High-level political participation—serving in appointed or elected office—was also mentioned in the Note, but little detail was provided on how to foster it.

In the Netherlands, few disabled people hold political office. Therefore, research was commissioned by the Dutch Ministerie van Binnenlandse Zaken en Koninkrijksrelaties (Home Office) to explore the participation of disabled people as elected or appointed officials in other European countries, including local, regional, national and EU governments. The focus was on factors that either hinder or lead to attaining elected or appointed office, including processes, practices, policies, laws, societal beliefs and personal

characteristics. The goal was to better understand how to tap the potential of disabled people in politics.

Methodology

A literature review was completed using a key words and synonyms-based search of articles indexed in Web of Science, IngentaConnect and Google Scholar from 1998 to 2018. Titles and abstracts were reviewed to eliminate obviously unrelated texts, followed by full-text review of the remaining articles. Additional articles were found via references in relevant texts. Recent Academic Network of Disability Experts country reports related to the European Pillar of Social Rights were used to establish key facts (Bengtson 2017; De Bruyker 2017; Nicolas and Ebersold 2017; Priestley and Lawson 2017; Schröttle et al. 2017). Non-academic sources, including news articles, speeches and published interviews with disabled politicians, were examined to add context and detail. Where material was in languages other than English, translations were made by the first author. A topic guide for semi-structured interviews was then drawn up based on themes derived from the expanded literature review.

Potential interview participants were identified via the non-academic sources mentioned above and the researchers' personal networks, with further possibilities located via snowball sampling. Persons with any impairment who were current or former appointed or elected officials were eligible for inclusion. Interview requests were then sent to over 40 disabled politicians and party activists in France, Germany, Belgium, the United Kingdom, Sweden, Norway and Denmark (countries close to the Netherlands, as requested by the Dutch Home Office), and to the Belgian, Hungarian and Greek presidents of the European Parliament's Disability Intergroup. In addition, one European political party with a unique campaign to improve candidate and activist diversity regarding disability was located and approached.

In total, nine semi-structured interviews were completed with current or former politicians, ministers and party activists, representing the United Kingdom, Denmark, Belgium and Hungary. All individuals contacted who agreed to be interviewed were included. Interviewees included persons with mobility impairments, visual or hearing impairments, and a developmental condition (autism). All interviews were conducted in English, via email or online videoconferencing, and informed consent was obtained. Respondents could choose to remain anonymous. Care has been taken to avoid details that might lead to accidental identification of respondents who chose anonymity.

Interviews were transcribed verbatim, and were coded by hand according to the original list of themes, and any new themes or sub-themes emerging from the interview data. Results were discussed by two researchers. From

Table 1. Key facts about disability and politics in five European countries.

Country	% disabled politicians?[a]	Employment quota?[b]	Equalities laws apply to elected officials?	Direct support for disabled politicians?	Conflicts between political work and benefits csystem?	Funded support available at work?[c]
Belgium	1.3–1.44%	3%	Y	N	N	Y
Germany	1%	5%	Y	N	Y	Y
France	1%	6%	Y	N	N	Y
Denmark	1%	n/a	Y	N	Y	Y
UK	1%	n/a	N	Y	Y	Y

[a]Estimates based on interviews and/or published sources, as no official data is available. We assume that there is an additional group who have, but do not declare, an impairment.
[b]Quotas regarding specific percentage of disabled workers apply to (some) employers.
[c]In all cases, personal care and disability-related support is limited and conditional. Denmark makes personal care support available at work or when volunteering more easily than others.

this process, six overarching themes related to barriers and facilitators were located. These were found not only in the interview data, but also in the academic and non-academic literature reviewed.

Results

In this section, key descriptive data regarding Belgium, France, Germany, Denmark and the United Kingdom is presented (see Table 1). This data estimates the percentage of disabled politicians, and establishes the existence of quotas, laws, policies and supports that might be expected to impact political participation of people with disabilities per country.

Next, results from both the literature review and interviews are presented in a series of sections and sub-sections based on the six categories of barriers and facilitating factors found: a) networks, b) recruitment and mentoring, c) resources (money, time and energy), d) the "hierarchy of impairments," e) accessibility of political spaces and activities, and f) laws and policies.

Finally, we present a brief case study of how one European political party is attempting to change its own practices.

Networks

Barriers to political participation of disabled people identified in the literature include isolation and decreased resources. Participation in a political party, from the level of local activist on up to running for office, requires time, energy and money. Success begins with having a large, strong personal network, a situation that naturally favours individuals from politically powerful families and those who have attended elite educational institutions.

France's Sciences Po offers an extreme example. As noted in a recent report, "all the different generations of French political leaders have met for the first time on Sciences Po's benches, and most of them have formed their

more solid friendship and network relationship by that time" (Algan et al. 2015). The doors of Sciences Po were closed to disabled students until quite recently. The fact that Damien Abad of the French centre-right party Les Républicains, who has a neuromuscular condition that limits his mobility, was both one of the first disabled students to graduate from Sciences Po in 2004, and then the first disabled French member of the European Parliament (Baudu 2009), illustrates that addressing educational and social exclusion can impact political participation. Abad's connections have enabled his rapid rise: having gained a municipal council post three years after graduation, he is currently one of his party's five national vice-presidents, as well as having held national office and serving in the European Parliament (Equy 2013; 20 Minutes Politique, 2013).

Some disabled politicians develop political capital through alternative means, including disability activism. For example, Horst Frehe, currently a Green member of the state parliament in Bremen, Germany, was a disability activist. He organised protests during the UN International Year of the Disabled in 1981, as well as setting up or working in multiple Disabled Peoples' Organisations (DPOs), including the European Network for Independent Living (ENIL). Frehe has noted that moving from a medical model of disability towards a social or human rights model empowers disabled people to have political influence, including as office-holders. He has also stressed the importance of developing disabled candidates at state/provincial level in Federal countries like Germany (Frehe 2008).

The career trajectory of David Blunkett, who is blind, offers another example. Blunkett was elected to Sheffield City Council while still a university student. He was active for 17 years in local and regional politics before becoming a Member of Parliament. Following formation of a Labour government in 1987, Blunkett was named as Secretary of State for Education and Employment, promoted to Home Secretary, and then Secretary of State for Work and Pensions. This would have been impossible without the opportunity to build a network at local and then regional level, because Blunkett had attended special schools for blind pupils, and came from a working-class background (Blunkett and MacCormick 2002).

Not every disabled person wishes to form their political identity around disability issues (Nishida 2016); there is also no guarantee that politically engaged disabled people will advocate for better disability policies (Percy 1989). However, "claiming" disability, understanding it as a common part of the human condition, understanding how impairment and social conditions intersect to produce disability, and recognising disabled people as an important minority group can impact formation of a political disability identity (Putnam 2005). As French municipal politician Jean Cristophe Parisot de Bayard, a wheelchair user and disability activist, has stated:

> I want the talents, the imagination, the fellowship [of disabled people] to be realities lived, wanted, defended. It is often our brothers, men who put barriers in front of us, without even knowing it or wanting to do so. But we are definitely living profound social change. (Parisot de Bayard 2014)

Political parties and organisations can encourage participation (Schur, *op cit*.). Most major political parties in Europe now have internal party caucuses or committees devoted to developing a larger pool of potential appointees and candidates who are female or from ethnic minorities, providing a boost to political neophytes from under-represented backgrounds. However, only the UK's Labour Party has made similar efforts regarding disabled people, with an independent society known as Disability Labour in existence for about five years. Its work is highlighted at the end of the *Results* section as an example of responding to participation barriers.

Recruitment and mentoring

Mentoring, either as part of a structured programme or on an unofficial basis, can help. For example, France's Abad states that his political rise began with being noticed as a student orator by French Member of Parliament Hervé Morin, who encouraged him to get involved in the youth branch of his party (Equy 2013).

Generic mentoring schemes exist to foster leadership skills amongst (usually young) disabled people, offering capacity-building and access to role models, including disabled role models (for example, see Office of Disability Employment Policy 2018). Information about formal mentoring schemes for disabled people seeking careers in electoral politics or policymaking was sought, but the authors did not locate any in Europe. However, several disabled politicians have highlighted the need for mentors, including Welsh councillor Fenella Bowden (Flint 2018). This was also mentioned as desirable by most interview subjects, but none had been part of a formal recruitment or mentoring programme.

A productive mentoring project might resemble the model developed by EMILY's List, an American organisation affiliated with the Democratic Party. Its Run to Win programme recruits, trains and supports pro-choice female candidates. Supported by donations, EMILY's List offers in-person and online training, and arranges mentorships. Over 10,000 prospective candidates have received support (EMILY's List 2018).

Leadership of unions and other civil society organisations is an alternative stepping stone to political life, so their successful recruitment and mentoring efforts can contribute to leadership development. The Public Service Alliance of Canada, which represents Federal and Provincial employees, is an example of a union with a well-developed research, outreach programme and

inclusion focused on leadership for "Equity Groups," a category that includes disabled workers (PSAC 2018).

Mentoring was also a top recommendation in the *Lord Holmes Review* (Holmes 2018) to redress poor representation of disabled people on public commissions in the UK, many of which focus on business or societal issues. This form of leadership is another pathway into political roles. Currently, only 3% of such appointees are disabled people, and a number of barriers exist in recruitment, application and hiring processes. Holmes suggested that the UK government should "establish a mentoring programme to support talented disabled candidates" (*ibid*., p. 8). He said disabled people should be proactively encouraged to join an existing mentoring scheme run by the Cabinet Office, which includes job-shadowing current commissioners and membership of advisory boards (*ibid*., p. 24). Crucially, commissioners needed to be pushed towards proactivity. As one contributor to the Holmes report stated, otherwise "people tend to be tapped on the shoulder by people who look like them, act like them, are educated like them" (*ibid*., p. 21).

Resources

The UK was the only country found where state funds have been made available to compensate disabled candidates for disability-related costs during political campaigns. In England, a £2.6 million Access to Elected Office fund ran for a few years, but was then closed. The loss of this support had a direct impact on candidates in autumn 2018. For example, one blind candidate had to ask family and friends to accompany her during door-to-door canvassing, because there was no funding for a personal assistant (personal communication, Fran Springfield, 29 October 2018). A campaign by cross-party political organisation More United (https://www.moreunited.uk) was instrumental in reinstating the fund at the end of 2018, and grants of up to £4000 were again available to local candidates in the 2019 election cycle. Funds can be used to cover costs such as Braille translation, sign language interpretation and specialist transport (Booth 2018).

In Scotland, a similar scheme has run successfully for several years, and is operated by Inclusion Scotland (2018). The fund was launched with a budget of £200,000. In its first year of operation, the Access Fund helped 44 potential candidates in Scotland, of whom 39 ran for office and 15 were elected. Based on the pilot's success at widening participation, the Scottish Parliament has committed to continuing the fund through 2021, when it will be re-evaluated (Young 2018).

One notable result from our interviews was that personal assistance (PA) services funded by EU states can have a major impact on political participation. If PA services are strictly limited to providing support for "activities of

daily living," e.g. eating, dressing, bathing and using public transport, those who want to volunteer for a political party, attend political meetings or campaign will be disadvantaged.

Time and energy are also important resources, and their lack can pose serious issues for people with some impairments. As Emily Brothers, a blind woman who has run for both national and local office in the UK, writes, this can lead to overwork:

> Despite our best endeavours, it often takes longer for a disabled person to accomplish a task. That is why so many successful disabled people work ridiculously long hours, which isn't possible if you experience fatigue because of your disability or health condition. (Brothers, in Brothers, et al. 2017: p. 32)

The organisation Disability Politics UK has therefore campaigned to make job-sharing possible for Members of Parliament (Disability Politics UK 2018). This would assist not only disabled people, but also those with parenting or caring duties. Although a court case by two Green candidates who wished to job-share (one a disabled woman, the other the parent of a disabled child) was dismissed, the influential Fawcett Society recently released a report (Brothers, et al. 2017) explaining how job-sharing could work in the British parliament, and advocating its use. It noted that job-sharing is already successfully used in the UK by judges, governors of utility firms, NHS executives, and policymakers in the UK Ministry of Justice.

Indeed, job-sharing and part-time working are well-established within civil service employment in many European countries, and there is no reason this practice cannot be extended to political appointees. Political parties could also innovate, and several European Green and feminist parties have already experimented with job-sharing arrangements. For example, leadership of the UK Green Party is shared between MP Caroline Lucas and Jonathan Bartley. However, job-sharing is usually prohibited by law for elected politicians.

In Belgium, there is a job-sharing-like process that gives disabled elected officials at local and provincial level the right to select a *vertrouwenspersoon* (confidential advisor) to assist them with their duties. This goes beyond providing a PA service, as it can include discussion of policies, but the *vertrouwenspersoon* cannot act as a proxy voter for the elected official. A letter from a doctor is needed to prove the need for assistance, and the *vertrouwenspersoon* cannot be a council employee (Agentschap Binnenlandse Bestuur 2018). The *vertrouwenspersoon* receives the same attendance fee as the council member they work with, which depends on council population size and can be as low as €400 per month, as local councillors are expected to do their work as a second job.

For example, a visually impaired politician from the CD&V party, Pol Verest, chose another CD&V member, Karl Tierens, as his *vertrouwenspersoon* when he gained a seat on the Ghent city council in 2013. Both received an

attendance fee. Verest and Tierens discussed council agenda items together and prepared what would be said, submitted to or requested of the local government by Verest, with input from their party (van Rossem 2013). However, only Verest took part or spoke in council meetings. For Tierens, the role provided a way to learn by doing: he soon successfully ran for a council seat, and Verest chose a new *vertrouwenspersoon* (HLN 2014).

No statistics were found about the number of Belgian politicians taking advantage of this possibility, or whether it has increased the number of disabled people running for office. The authors were able to find three examples of currently serving *vertrouwenspersonen*, in Hulshout, Mannu Dox and the aforementioned example of Ghent, of whom two were working for visually impaired politicians and one for a politician with a hearing impairment.

There is also a potential downside to job-sharing arrangements: those who job-share earn part-time wages.

The "hierarchy of impairments"

The term "hierarchy of impairments" is used to describe how perceptions of and attitudes toward disabled people often depend on the type of impairment they have and how it occurred (Hernandez, Keys, and Balcazar 2000; Deal 2003.) Whether an individual's impairment is viewed positively, negatively or as a neutral factor depends largely on cultural factors, so this will vary between countries, but there is a rich literature indicating that persons with cognitive impairments are typically judged as less deserving than those with physical or sensory impairments (for example, Thomas 2000; Harpur, Connolly, and Blanck 2017). This has deep roots in the way that disability has been culturally constructed, and with the function of that construction within culture (Snyder and Mitchell 2010). Self-stigma—having a negative view of oneself because of a disability—can form a powerful barrier to achievement as well.

When it comes to politics, it appears that impairment through military service can be a driver rather than a barrier – someone with the same level of impairment from birth or due to an accident is far less likely to win office than a war veteran, such as the late Sen. John McCain in the US, or someone who has otherwise acquired their impairment in the line of duty, such as Wolfgang Schäuble, former Minister of the Interior for Germany and current President of the Bundestag, who was partially paralysed by an assassination attempt in 1990. Symeonidou (2009) also noted the higher status of DPO members who are war veterans in their interactions with politicians in Cyprus.

Certain impairments, such as mental ill health or intellectual disability, may be more likely to trigger adverse reactions than others. For example, we

found that when the Belgian Green Party ran Tane Depuyt, a young party volunteer who has Down syndrome, as a candidate for his local council, reporters often asked if it was some kind of attention-getting stunt (De Bastelaere 2018). Even in disability-focused roles, some impairments can be seen as a barrier to public service (Baker 2011). In the US, the appointment of Ari Ne'Emen, an autistic adult with a BA in Political Science and a DPO background, to the National Council on Disability (NCD) sparked controversy, with some parent-activists vitriolic in their opposition. Though blocked for six months, eventually Ne'Emen was able to join the NCD (Diamant 2010). He served two terms, including as chair of the Council's Entitlements and Policy and Program Evaluation committees. "The level of prejudice was pretty shocking," he told journalist Steve Silberman. "Some people relied on outrageous but all-too-familiar stereotypes to claim that it doesn't make sense to have an autistic person on the National Council on Disability, such as the bizarre notion that autistic people are emotionless sociopaths" (Silberman 2010). Ne'Emen's comments, and the reaction of the Belgian media to Depuyt's candidacy, are reminders of the way people with intellectual and developmental disabilities are socially constructed as being unable to meet societal demands (Wendell 1996)—regardless of their level of demonstrated ability.

Accessibility of political spaces and activities

Of course, access to voting is considered the first level of political participation, with the ability to run for office following on from it (European Union Agency for Fundamental Rights 2010). Evidence indicates that not only does voting increase political participation amongst people from disadvantaged groups, the electoral success of persons from these groups can positively impact the level of voting amongst their members (Logan, Darrah, and Oh 2012).

While many countries are giving attention to voting accessibility (for example, see Hees, Boeije, and de Putter 2017; Willis et al. 2016), political spaces beyond the voter's booth, from local meeting rooms to the debating chambers of national parliaments, also present barriers. This was highlighted in both the literature and interviews. For example, Dame Anne Begg, a wheelchair user and UK Member of Parliament from 1997 to 2015, faced accessibility barriers:

> The House of Commons isn't as accessible as it could be and she was unable to sit directly alongside other MPs in the chamber, but it didn't bother her. "I remember after getting elected, someone saying: 'It's terrible you stick out in the aisle, they haven't cut a bit out of the green benches for you to slot into'." Begg says she wrote back and said: "I've been invisible for far too long, I'm glad that you noticed I'm there." (Rose 2015)

Obviously, everyday accessibility issues, such as access to public transport or adapted vehicles, will also impact participation. Availability of sign-language interpreters for Deaf persons, and screen-readers or Braille translations for blind persons, is also crucial—but these services add costs that politicians without disabilities do not bear. Importantly, it is not always clear who pays for reasonable adaptations or PA services when it comes to elected officials. Respondents also said that the media need educating about dealing with politicians who use sign language interpretation, and poor access to media outputs can hamper their work-related research.

Welsh councillor Anita Davis, who is blind, said she found it hard to make decisions when information was not provided in accessible formats, and when participants in meetings forgot to identify themselves. She noted that canvassing door-to-door also posed challenges:

> I didn't know the layouts of the wards I was covering, so I wouldn't necessarily know if someone had steps or a ramp, or just how to find the front door. So I had a number of accidents where I fell down the steps or couldn't get in the gate. (Davis, in Flint 2018)

When governments and political parties assume everyone has the same capabilities, they automatically exclude people with disabilities.

Laws and policies

A number of laws and policies were found that could have an impact on political participation (see Table 1 for a comparative overview). These included laws and policies regarding employment of disabled people, conflicts between political work and disability benefits, and policies on provision of personal assistance or funded support at work, as described in the following themed sub-sections. Funded support for disabled candidates was described previously in the sub-section *Resources*.

Laws and policies regarding employment

Laws establishing disability employment quotas might be expected to have an eventual impact on the number of disabled politicians and political appointees, since employment builds a personal network, and can result in a higher public profile. However, there was no appreciable difference between countries with and without such quotas (see Table 1). For example, there are specific Acts in both the Flemish and Walloon areas of Belgium, and in the Brussels-Capital region, to improve representation of disabled people in public employment. A 3% quota was set by decree in 2007, although this figure has been an official goal since the 1970s (Stevens 2018). However, only six federal departments have reached this low target. In 2016, the average employment rate for disabled people in departments of the Federal

government of Belgium was 1.44% (De Bruyker 2017). In the Flanders government, the figure was 1.3% (Stevens 2018).[1]

The Belgian quotas are unenforced, are not well known, and do not apply to political candidates. As Annelies van den Brande, a 2018 candidate for Groen Sint-Niklaas who has a visual impairment, told us: "In Belgium there are no quotas or rules concerned with making it easier for people with disabilities to be elected or to give them extra help in politics" (personal communication, Annelies van den Brande, 25 October 2018).

In France, a 2005 law requires all companies with 20 or more employees, including governments and government agencies, to employ 6% disabled people. However, there are many ways for employers to be exempted from the law. Interestingly, this law also created the *Fonds pour l'insertion des personnes handicapées dans la fonction publique* (FIPHFP, Fund for the Inclusion of People with Disabilities in the Public Service), which uses fines collected from government employers (as none are currently meeting the 6% quota) to fund supports and training, hold events for public employers to encourage them to hire more disabled people, and publish guidance on reasonable adaptations and improving recruitment practices (FIPHFP 2018).

In Germany there is a 5% hiring quota regarding persons with "severe" impairments. Just over 25 percent of employers currently meet the quota, which also applies to governments. Non-compliant employers pay a very small fine (currently 125-320 euros per month). These funds go to the Federal Employment Agency (BMAS), with 30 percent going to an "equalisation fund" used to support disabled people who are transitioning into employment, including subsidies to employers (European Commission 1999; Cuppage 2013). In practice, this fund mostly benefits young school-leavers. Some of the remaining 70 percent goes to other employment projects for disabled people, such as social workplaces.

Denmark has no quota scheme, but employers are required by law to interview all qualified disabled people. A small wage subsidy is also available to employers, and there is a permanent "flex job" subsidy paid to employers of disabled part-time workers.

The UK also has no quota. Some flexibility in work hours is possible, but employees have to ask their employer directly, and employers can refuse. Employers are responsible for adapting work tasks and workplaces. Employees can seek redress via the Advisory, Conciliation and Arbitration Service (ACAS). In reality, help from ACAS is difficult to access, and employers have many ways to avoid spending money. The UK's Access to Work scheme, which can provide job coaching, interview support, communication support and PA support, is not available to elected officials.

The UK Equality Act 2010 prevents discrimination in employment and requires employers to make reasonable accommodations for workers with disabilities. It covers paid employees, but not elected officials (HM Government 2010). As a result, a disabled Member of Parliament (MP) interviewed for our research has struggled considerably:

> There are no laws or official policies relating to disabled people in public life.
>
> I have had a number of access issues unresolved, as Parliament has refused to make adjustments for me to certain practices which I needed for my disabilities in order to do my job to the best of my ability. These include access to remote electronic voting/proxy voting as and when needed on the occasions my disabilities mean I am unable to attend Parliament, for other MPs not to shout and heckle whilst in the chamber whilst somebody is speaking (an archaic and childish practice they are particularly keen to preserve), guarantee of a seat in the chamber at busy times as I cannot stand for very long and there are not enough seats for every MP, and disability awareness and equality training … for every elected official and their staff.
>
> I also have asked Parliament to do more to promote equality and raise awareness, and this too has been rejected. Ignorance towards my disabilities and how they affect me, and a lack of commitment to disability equality and awareness in both Parliament and the UK at large, has affected my ability to do my job and has also harmed my mental health. (Personal communication, Anonymous, 18 September 2018)

This MP further noted that while some support is available through the Independent Parliamentary Standards Authority, it is not guaranteed, and MPs may have to cover some costs themselves.

Conflicts between political work and disability benefits

In Germany, the state provides personal assistance and transport support for some disabled workers. This includes persons who do not receive disability benefits. However, support is means-tested, so a person elected or appointed to a post with a reasonable salary might then lose their access to personal assistance, and need to pay privately. Such support can be quite costly. As disability activist Christian Bayer told the Independent Living Institute, this can form a barrier for disabled people: "I don't want to pay for my assistance, so I work part-time to avoid exceeding the income level. If the level were higher, or if there weren't a limit, I would be able to work more" (Bayer, in Bernt 2008).

By contrast, support for daily life requirements, such as PA service, were neither attached to being in receipt of benefits nor means-tested in Denmark until recently. Support in work could be provided for up to 20 hours per week. However, benefits have now been cut for disabled persons who work fewer than 225 hours per month or who have a working partner. These changes have had an especially high impact on those under age 40.

Sarah Glerup, the first disabled person to serve in the Danish parliament when she briefly provided cover for a Red-Green Party colleague who was on leave, noted that the Danish benefits system can create very direct barriers for disabled people who are interested in political life. These can apply not only to office-holders, but also to activists and volunteers:

> In recent years we have seen examples of people receiving disability pension who have been bullied by authorities into giving up running for local offices or even participating in public political debates. They have been told that they might lose their pension if they remain politically active, because it will be seen as a sign that they are able to work and do without a pension. (Personal communication, Sarah Glerup, 17 October 2018)

Glerup added that availability of high-quality PA services is a crucial facilitating factor for politicians who, like herself, have severe impairments:

> The most important factor/policy when it comes to my participation not just in political life, but in society as a whole is the fact that I am entitled to a personal care assistant 24 hours a day. This is the only reason I can live independently and work in spite of a very severe disability (I cannot walk or even breathe on my own). Without our PCA policies I would be stuck at an institution or dead. (ibid.)

In another example of benefits-based barriers, local councillors in the UK receive a small allowance to cover the costs of undertaking public service. This money is not considered a salary for tax purposes, so recipients cannot top up their income with Working Tax Credits. However, the benefit system considers it "personal income" and cuts means-tested benefits accordingly. This policy has a pernicious effect on disabled people and single parents, explained Labour Party activist Fran Springfield. Springfield also pointed out that benefit payment errors can leave local councillors behind on their rent or Council Tax. It is against the law for debtors to stand for office, and they can be suspended due to arrears if already in office (personal communication, Fran Springfield, 29 October 2018).

Funded support at work

In Belgium, direct services such as job coaching, work adaptations, travel support and sign-language interpretation are funded by regional agencies, with work often carried out by external organisations. Nieuw-Vlaamse Alliantie MEP Helga Stevens, who is deaf, noted that the way sign-language interpretation is provided could be a facilitator or a barrier. "The Flemish government has a policy since 1994 to pay for sign language interpreters in work situations (10% of the working time, be it as employee or as self-employed person—with a possibility to double this upon motivated request) and private situations (very limited: 18 hours a year which can be doubled)," she said.

Stevens said it took time for her party to understand how to work with a deaf person. "I contributed as a volunteer to the internal working group 'Policies for persons with disabilities' of the predecessor to my party—this way the party had the opportunity to get to know me and to observe how I can function with sign language interpreters," she noted. "As a self-employed person I was able to use my sign language interpreters more flexibly, compared to other deaf persons who are employees—they need the signature of their employer to be able to use work-related interpreting hours" (personal communication, Helga Stevens, 24 October 2018).

Stevens highlighted how different rules about providing support for disabled people in politics can impact carrying out their duties:

> At the Flemish Parliament I was immediately provided with sign language interpreters. It took a short time to find the right working formula, but ever since then, the Flemish Parliament has been excellent in following up and paying the SL interpreters. They even paid for SL when related to my parliamentary mandate, e.g. working visits, meetings with citizens, local party branch meetings, national party meetings, etc.
>
> When I became member of the Belgian Senate, I pressed them to adopt the same system as used by the Flemish Parliament. A joint agreement was made to avoid overlaps and double finance, which is of course logical.
>
> In this regard, the European Parliament is less flexible. They refuse to pay for non-official meetings… so for these meetings I fall back upon the Flemish system for reimbursement of expenses for work-related SL interpretation. However, I am pressing the issue within the European Parliament, as it is unfair that SL interpretation requested by external people to attend official meetings such as plenary sessions, committee meetings at the European Parliament are hired on the same basis as the spoken language interpreters, while my sign language interpreters have to work under different conditions, and are paid less and do not enjoy the same benefits as the interpreters hired by the Parliament itself. (ibid.)

As in Stevens's case, conflicts may affect disabled politicians and appointees who receive recognition of their disability or services from a municipality or state when they begin working in a nation's capital, as well as those who move to another country—for example, to take up an EU post. While some disability-related supports are portable across state or even national borders (for example, special parking permits for people with disabilities issued by EU states can be used throughout the EU), others could be lost or only retained with extra paperwork (Eichhorst, et al. 2010).

Stevens's experience within the Nieuw-Vlaamse Alliantie also illustrates that a party can develop a volunteer into a policymaker and then a candidate. Indeed, political parties have a key role to play. They train and develop volunteers, recruit and run candidates, and select political appointees. Research regarding representation of women and ethnic minorities in electoral politics suggests that "systemic biases inherent in candidate selection

procedures … render representative democracy less legitimate than it could be" (Bird 2003). However, we found that so far, most parties have neglected addressing systemic disability bias within their own ranks.

Case study: The potential role of political parties

Here we present a brief case study of Disability Labour, which shows how one European party has started to take positive action. It suggests tools and practices that can be adopted to produce change.

Within the UK's Labour Party, Disability Labour (see https://www.disability-labour.org.uk) serves as an independent policymaking group on disability issues, and also aims to support and develop disabled party members to serve as policymakers, ministers and elected officials. Although its tenure has not been without controversy (Pring 2018), it provides disability equality training to local party branches and campaigns internally for improved access to party activities for disabled members (including remote access to party conferences and annual general meetings). Party conferences are where alliances are solidified, internal leadership decisions are made, and policies are finalised, so these have been a particular focus.

Disability Labour member Kathryn Bole, also a Labour councillor for Whitton/Whitehouse, said its role is "to raise awareness of the issues that disabled people have coming to the party and participating. It's still filled by grey-haired old men: they don't adopt the technology, they're not as open to change. And I think there is a 'political correctness' taboo to asking people about how their disability affects them."

Bole, who had previously been active on disability issues in her trade union, was surprised at the lack of knowledge about access issues in the party. "How many of the things people think are simple are holding people back – like door-knocking," she noted. "I happen to use a power wheelchair, and that's not going to work very well. [To be selected as a candidate] in the Labour Party, you have to go before a team of people, your local campaign forum. The first thing they ask is how many doors you've knocked on, how many leaflets have you delivered" (personal communication, Kathryn Bole, 29 October 2018).

Disability Labour are also working to improve support for candidates and appointees. Co-chair Fran Springfield offered the example of Marsha de Cordova, a recently elected Black MP who is visually impaired. "She's been an MP since last year, and even now the House of Commons can't get her papers to her on time in order to be able to read everything before debates start," she said. "All she needs is large print, not Braille! They did it for David Blunkett, but he was a cabinet minister." Working as a political appointee can also trigger access problems, she added. "You have to be fit to work in

the House! The building is incredibly hard to get around if you have any form of disability, and if you're a wheelchair user, heaven help you. Last time I was there, it took me half an hour to get from the gate to where I wanted to be" (personal communication, Fran Springfield, 29 October 2018).

According to Bole and Springfield, changes to working practices, working spaces and information could all improve inclusion. Also important is recognising and developing disabled people in the party so they can attain higher posts.

Discussion

Many commonalities were seen in the accounts of political life shared by our disabled research respondents, and those found in the literature review. Both facilitating factors and barriers were described and categorised.

First, participation starts with voting, activism, party volunteering and local races. Experiencing these forms of basic participation encourages the formation of political action and ambition.

Second, a clear link was observed between increased inclusion in education and society, and political participation. At EU level, fewer than half of people with disabilities are in employment (Grammenos et al. 2013). Barriers to employment of disabled people have an additional effect of limiting access to political life, as business, workplace or union leadership are often precursors to political leadership. Programmes to recognise and develop the talents of disabled employees, whether run by governments, employers or trade unions, could help. Few politicians interviewed had previously held governance roles in business or societal organisations, other than those whose background was with DPO governance. However, disabled people in such governance roles represent an untapped resource for parties seeking experienced, knowledgeable potential recruits for candidacy or ministry work.

Third, several respondents said that greater visibility of disabled people in politics could help to bring about societal change. This includes serving as role models for other disabled people, and providing an example of what disabled people can accomplish. However, success often requires practical support. As the British MP interviewed said: "A number of my constituents whom I represent are glad to have a disabled MP representing them… [but] my disability made both my election campaign and my time in the role since my election harder than it would be for a non-disabled candidate and MP."

Kristian Hegaard is currently a member of a municipal council in Denmark but also served briefly as a member of the Danish Parliament, where he acted as Speaker for Foreign Affairs and Defence. He said:

> First of all, I think young people with disability need role models. Maybe there should be some kind of quota in the parties, or talent-developing in youth disability organisations with the focus on becoming a politician. (Personal communication, Kristian Hegaard, 16 October 2018)

Like Hegaard, who was first elected at age 18, disabled people who currently serve in public office or as appointed officials tend to be exceptional over-achievers, and are therefore excellent role models. The number of high-profile disabled politicians is limited at national or EU level, but there is a larger, less visible group of provincial and local politicians and policymakers who are also making very valuable contributions. If a way could be found to bring them together, they would also represent a fantastic "brain trust" for how to recruit, encourage and develop disabled politicians of the future.

Fourth, in most countries, there were no policies that specifically supported politicians or political office-holders. France presented a partial exception, because the state used funding raised from fines on government employers to fund recruitment, development, and other services for disabled persons in public service. However, so far this programme has had a limited impact. The Access Funds in England and Scotland, on the other hand, appeared to be an effective way to ensure disabled candidates have the support they need.

Campaigners and office-holders in some countries were able to benefit from publicly funded PA or communication support while carrying out political work. However, access was often described as limited or uncertain, and some respondents described conflicts between funders that impacted the form and amount of support they could have.

Although national employment quotas did not appear to impact the percentage of disabled politicians and political appointees, the establishment of quotas for disabled candidates by political parties might. Precedents abound of voluntary quotas for women or ethnic minorities, and quotas have been demonstrated to increase women's political participation (O'Brien and Rickne 2016). Efficacy will depend on the attitudes towards disability held by party members (Morgenroth and Ryan 2018). The experience of developing women's leadership in NGOs suggests that training and mentoring are required, as is dismantling cultural and systemic barriers (Abdela 2000).

An example mentioned by our respondents is the existence of cultural, procedural and legal barriers to job-sharing. Job-sharing in public office and senior policy roles could solve problems for disabled people, especially those whose stamina is affected (Brothers, et al. 2017). For appointees, the issues would be the same as for other high-level employees who job-share. Ministers could be encouraged to consider whether two part-time appointees could bring more to a role than one full-time appointee. This could broaden access not only for disabled people, but also for people with caring

responsibilities. Success would require developing disability-inclusive lists of potential appointees, and training promising individuals.

For elected officials, job-share partners would have to run for office as a team, and the team could have only one vote. Where there is a difference of opinion within the team, the team might have to abstain. Alternatively, an elected job-sharing team could divide the job temporally (mornings/afternoons or seasonally) or by task (e.g. work in the chamber and work at constituency level) (Campbell and Childs 2017).

The Belgian *vertrouwenspersoon* provision for disabled elected officials is a different, more limited and unequal form of job-sharing. It would also require legal change, and funding.

Benefits policies were mentioned by respondents in all five countries as having unintended consequences for politically active recipients. Removal of such barriers could encourage some disabled people to run for or continue to serve in office.

Limitations

This research is based on a literature review and a small number of interviews, which were obtained from an opportunity sample. Broader investigation is needed, including investigation of the experiences of disabled politicians who choose to conceal their impairment, and examination of which policies and practices are most effective for encouraging representation of disabled people in politics.

Conclusions and recommendations

To conclude, the level of inclusion in political life of disabled people does not match the percentage of the population who have an impairment in any European country investigated. Disabled people face somewhat different cultural, economic, support or access barriers in the various EU countries, and within different regions of those countries as well.

Potential solutions were located at the policy and legal (systemic) and party levels.

Inclusion in education, work, societal groups and public spaces clearly impacts on access to political activity, and is dependent on policy and legal frameworks. Crucially, inclusion in education and work provide the foundation for inclusion in political life: it is from this basis that leadership emerges. Universities offering political science, governance or similar programmes should actively seek qualified disabled applicants, and ensure they have the right support. (Higher) education institutions should also attempt to identify and nurture emerging disabled leaders in all subjects, as these individuals could be the policymakers or ministers of the future in their areas of specialism.

Ensuring that personal assistance and other support is available and funded for disabled candidates, appointees and office holders is essential to level the playing field. Legal and policy barriers, including those based in disability benefits systems, must be addressed.

Political parties can act to welcome and support disabled people as political actors at the entry level—as voters, in debates, as members, and as campaign workers and volunteers. They should also develop targeted strategies for recruiting and developing potential disabled candidates or appointees. Parties could be helped by internal or independent organisations, such as DPOs. Political parties could use quotas to encourage selection of disabled candidates or appointed officials. Practice change may be needed in areas such as job-sharing, meeting and communicating. Universal Design principles can provide guidance and inspiration (Hamraie 2017). Strategies can best be developed with input from disabled people themselves.

Mentoring schemes aimed at recruiting and developing potential disabled candidates and political appointees could be launched by states, political parties, societal organisations or partnerships of these entities. In the EU context, a European scheme to develop political leadership by disabled people in all member states could expand impact. Mentoring should not be restricted to young people—disabled people who have gained experience in governance of companies, NGOs or DPOs are obvious choices for public service in appointed roles or political candidacy.

Finally, robust and trustworthy data needs to be collected at all levels of political life: local, provincial, national and European. Without firm numbers, it is impossible to gauge progress towards greater inclusion of disabled people. Improved data collection throughout the EU has also been called for by the OSCE Office for Democratic Institutions and Human Rights, which stated: "At the national level, comprehensive, sex- and impairment-disaggregated data are necessary to direct immediate action, as well as to monitor, and correct where needed, interventions and progress achieved over time" (OSCE/ODIHR 2017).

Note

1. While technically government and civil service employment is a separate world from that of holding appointed political posts, in this and the sections that follow it is used to examine participation in broadly similar government work. In no case were quotas found that applied to appointed roles, for which candidates are chosen by ruling political parties.

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