**Document 2**

**EDF’s advocacy paper on Social Protection for the new EU High Level Group on Social Protection and the Welfare State**

**Document for discussion**

**Purpose of this item**

The purpose of this item is to get feedback from the Committee members on this new advocacy paper. This feedback can be sent in writing prior to the meeting, or orally during the meeting itself.

The document will be sent to the new EU High Level Group on Social Protection and the Future of the Welfare State to help guide them in their work, and to make them aware of key areas where disability issues should be addressed.

The document does not aim to address all social protection issues, but simply those that we consider the most pressing and that could be best addressed at EU level rather than purely on a national or local level.

**Questions for members?**

Do you have any comments or suggestions for changes to the document before it is sent out?

Do you have any recommendations for how else you would like the document to be used for advocacy purposes?



Social Protection and the Welfare State: What the EU can do to support persons with disabilities

European Disability Forum Position Paper

By Haydn Hammersley | February 2022

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# Introduction

#### The European Disability Forum

The European Disability Forum (EDF) is an independent NGO that represents the interests of 100 million Europeans with disabilities. EDF is a unique platform which brings together representative organisations of persons with disabilities from across Europe. EDF is run by persons with disabilities and their families. We are a strong, united voice of persons with disabilities in Europe.

## Executive Summary

Social protection and the welfare state are generally areas in which the Member States, and even regions and local authorities, lead the way. The division of competences between the European Union (EU) and its 27 Member States has typically left the EU with little say on social protection and welfare[[1]](#footnote-1). However, with the proclamation of the [EU Pillar of Social Rights](https://ec.europa.eu/info/strategy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights_en), the increasing focus of the [European Semester](https://ec.europa.eu/info/business-economy-euro/economic-and-fiscal-policy-coordination/eu-economic-governance-monitoring-prevention-correction/european-semester_en) on social issues, and the role EU funding is playing in supporting social inclusion, this trend appears to be reversing.

The EU’s movement towards a greater focus on social issues is very timely, not least because a number of issues concerning social protection and welfare, particularly those which have been exacerbated in recent decades, would be more aptly addressed at EU level than at national or local level. This seems to be something the EU institutions are increasingly aware of, and has been reflected in the recent creation of a [High Level Group on the Future of Social Protection and the Welfare State in the EU](https://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=10101&furtherNews=yes).

In this paper we will outline a selection of the most pressing issues related to social protection for persons with disabilities, as well as how and why they could be most effectively addressed at EU level. This is to say, we do not seek to outline the most urgent social protection needs for persons with disabilities in general terms, but merely those that it would be best addressed by harmonised across the entirety of the EU. Furthermore, we must point out that this is not an exhaustive list of issues, and that there are many more that could become more urgent and require EU-level action in the future. Each of our thematic sections will conclude by giving recommendations on how the EU could take action to address these.

# Current context

Inflation and an unprecedented increase in cost of living for Europeans is putting persons with disabilities at increasing risk of poverty[[2]](#footnote-2). According to Eurostat, in 2020 56.1% of persons with disabilities in the EU had at least some difficulty making ends meet (being able to cover their basic needs) and 11.2% had “great difficulty” making ends meet.[[3]](#footnote-3)

In some EU Member States the situation is even more striking. In Bulgaria, for example, 90.3% of persons with disabilities have at least “some difficulty making ends meet” and 28.5% have “great difficulty making ends meet”. In Greece, a total of 92.3% of persons with disabilities in have at least some difficulty making ends meet and 41.1% have great difficulty making ends meet.[[4]](#footnote-4)

The persistence of the COVID-19 pandemic and the drastic increase of energy and food prices[[5]](#footnote-5), are likely to result in the figures mentioned above being far more worrying now in 2022 than they were two years ago when the last data was collected. This further increase to cost of living is putting the already limited support offered by disability allowance and support services to the test.

As we will see in this paper, beyond general increases in cost of living, the risk of persons with disabilities falling into poverty is also greatly enhanced by the extra cost of living that comes with having a disability[[6]](#footnote-6). In the EU context, persons with disabilities are also impeded from improving their financial situation because of inflexible social protection systems that make taking up paid work potentially very risky to the stability of their income, and by making it extremely difficult for persons with disabilities to enjoy their free movement throughout the EU as EU citizens.

# What the UN CRPD says about social protection and welfare

The obligation of States Parties to provide adequate welfare and social protection schemes to support persons with disabilities is clearly laid out in the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)[[7]](#footnote-7), signed and ratified by the EU and all its Member States. It is best encompassed in Article 28 on “Adequate standard of living and social protection” but is equally referred to in Article 16.

Below you can see the relevant extracts from these two articles. They refer, among other things, to the right to an adequate standard of living, to social protection and poverty reduction schemes, and to assistance with disability-related costs.

## Article 16 - Freedom from exploitation, violence and abuse

States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

## Article 28 - Adequate standard of living and social protection

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

 (a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;

 (b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;

 (c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;

 (d) To ensure access by persons with disabilities to public housing programmes;

 (e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

# Freedom of movement and mutual recognition of disability status

Fragmentation of disability assessment systems has led to a fractured understanding of what disability is and who qualifies for social protection and benefits. The EU provides citizens with opportunities for mobility in countries other than their own. Today, 17 million EU citizens live and work abroad in another EU country[[8]](#footnote-8). This mobility, however, is extremely limited for persons with disabilities.

The inconsistent types of assessment, qualifications for benefits and administrative processes inherently deprive persons with disabilities of their right enshrined in the EU treaties to freedom of movement (Article 3(2) of the Treaty on European Union (TEU)[[9]](#footnote-9) and Articles 20, 26 and 45-48 of the Treaty on the Functioning of the European Union (TFEU)[[10]](#footnote-10).

While the CRPD provides a description of what constitutes a disability, the assessments of disability are not always in-line with this. A person may qualify as “disabled” in one country but not in another. There is great variance for the process to be registered as disabled and then to begin receiving social support. There are different types of qualifying criteria, assessment methods, assessors and supporting evidence required.

This makes navigating the process and system difficult in one’s home country and even more difficult abroad. If a person with a disability were to move to a new country, it would be difficult for them to register again as disabled and to receive their social protection, meaning they may experience time with no social protection at all, often unable to keep their protection from their last country of residence.

In practice, most persons with disabilities cannot afford to take the risk of forgoing any type of support or recognition of their disability, especially during the crucial moment in which they are acclimatising to work or studies in a new country. As such, most persons with disabilities are *de facto* denied their right to freedom of movement, one of the cornerstones of rights afforded by the EU treaties.

## What could the EU do to address this situation?

In its new EU Strategy on the Rights of Persons with Disabilities[[11]](#footnote-11), the European Commission has committed to addressing the issue of mutual recognition of disability assessment, and to establishing an EU Disability Card. We believe these are things the EU’s new High-level Group on Social Protection and the future of the Welfare State could be part of forming.

The EU Disability Card is going to be one of the flagship initiatives under the Disability Strategy. It will be one of the actions that shows EU citizens the very tangible difference that EU can make in their lives. We would like the EU Disability Card to be the means by which disability status in one Member State is mutually recognised through the 27 Members of the Union, at least when a person is temporarily staying in another member state such as for holidays, internships, or when studying abroad.

It is important that the Card is accepted in all Member States and that it is supported by a Directive or Regulation to make it legally binding. The Card, as a means to mutual recognition of disability status, should be the basis for which a person with disabilities can begin to request access to support services in their host country, thus speeding up the process of getting necessary support by removing the need to be reassessed for one’s disability.

**We would therefore like the High Level Group to work alongside European Commission in ensuring this is the case when the plan for the Card is drawn up, ready for release by the end of 2023.**

For now, it seems like the scope of the Disability Card is limited to the mutual recognition of disability status and the right to accessing certain advantages in the areas of culture, leisure, sport, and possibility transport. However, it is important to also look into the possibility of transferring social security benefits such as disability benefits when moving (temporarily) in the European Union. This is an issue for persons with disabilities going abroad for limited periods of time in order to, among other things, join a partner, do an internship, or study for a limited amount of time in another Member State. It is already possible for unemployment benefits and for emergency medical treatment with the European Health Insurance Card, but not for disability benefits. This particular issue is unlikely to be solved by the Disability Card, at least at the first stage, but could be addressed by the Commission and the Member States by way of agreements to temporary transferability of benefits and services for temporary stays in other Member States. At a later stage, the Disability Card could also include it once it is firmly established and recognised.

In order to be able to navigate social protection systems in other EU Member States, it would be beneficial to create an accessible and centralised online information platform giving persons with disabilities information on the services to contact when moving throughout, in order to make all persons with disabilities the support they are entitled to and to tackle the issue of “non take-up” of benefits.

# Compatibility of disability allowance with other forms of income

## Compatibility with salaries

The employment rate of persons with disabilities in the EU is 24.5 percentage points lower than it is for persons without disabilities[[12]](#footnote-12). There are many reasons for this but one of the main issues, and one linked directly to the issue of social protection, is the incompatibility between support from the State in the form of disability allowance, and other forms of income such as salary, home ownership, or even the earnings of a spouse of household member.

Disability allowance or “disability benefits” are a right for persons with disabilities and are intended to help compensate for the extra costs of living incurred in a society that is generally inaccessible and requires persons with disabilities to pay for their disability-related needs out of their own pocket. Persons with disabilities notably spend a lot more than persons without disabilities on things such as:

* Personal assistance
* assistance in taking care of certain administrative / household chores
* Accessible housing
* Transport and adaptions to means of personal mobility
* Assistive devices and technology
* Additional medical bills

Research from the University of Linz (Austria) and the University of Salamanca (Spain) suggest that having a disability increases the annual cost of living by an average of 23,000€ in Sweden, and over 20,000€ in the Netherlands and Denmark.[[13]](#footnote-13)

Disability allowance is rarely enough to compensate for these costs as it is. When a person with disabilities then tries to improve their financial situation by taking up paid work, in almost all Member States they are penalised for doing so by losing their disability allowance[[14]](#footnote-14). In the few Member States that allow you to retain some allowance, this is only for a limited period of time, or for earnings up to a very low threshold before the right is lost entirely, and often irreversibly.

It is a huge risk to take, and too often means persons with disabilities who do work are still living in poverty because of how much more expensive their living costs are than for persons without disabilities. Eurostat shows that 11% of persons with disabilities who have a job live below the poverty line[[15]](#footnote-15).

## The “love tax”

In the EU we see a phenomenon which is sometimes referred to as a “love tax” or the “cost of love”. When a person with disabilities receiving disability allowance or support in the form of service gets married, has a civil partnership or a legal cohabitant, their entitlement to benefits or support is re-evaluated in line with the income or assets of their partner. The result is that persons with disabilities either see their support reduced, or disappear entirely, despite the fact that the provision of disability allowance and service provision should be based on the barriers that they personally face as a person with a disability.

Persons with disabilities are therefore punished unfairly when they get married or register a partnership, on the basis of the income or even the disability allowance of their spouse. Women with disabilities are particularly impacted by these cuts to their allowance. Beyond the risk this poses to the financial stability of persons with disabilities, it also undermines their rights in matters relating to marriage, family, parenthood and relationships, as outlined in article 23 of the UN CRPD on “Respect for home and the family”.[[16]](#footnote-16)

## What could the EU do to address this situation?

We believe the EU needs to take a lead in pushing for a recognition of the fact that disability allowance is not a gift to persons with disabilities. It is a right and it is there for a reason. It is a compensation for all the financial barriers persons with disabilities face. Taking it away when a person with disabilities tries to enter the labour market is akin to condemning many persons with disabilities to always remain poor and to never have the same right to improve their economic standing as persons without disabilities.

We want concretely for the High Level Group on Social Protection and the Future of the Welfare State, alongside the European Commission, **to push the Member States to allow persons with disabilities to retain their disability allowance when they begin to work, and when they get married.** This will provide the security needed to bring far more persons with disabilities into the labour market, increase the working population of the EU, and allow them to pay back revenue by way of taxation on their earnings. It will also assist all the Member States in upholding their obligations under Articles 23 (Respect for home and the family) and 27 (work and employment) of the UN CRPD.

# Ability of disability assessment to identify individual needs

The challenges associated with disability assessment are numerous. To begin with, the process can be lengthy and arduous and, in some cases, undignified. The methods used can also be restrictive and fail to consider the true barriers people face in their daily lives as persons with disabilities. An assessment that does not truly consider the societal barriers the person with disabilities faces, combined with what are often restrictive social protection budgets foreseen for persons with disabilities, result in many persons with disabilities not getting the support they need after being assessed as having a disability.

We also see particular difficulties for persons with “hidden” or “invisible” disabilities who can be misdiagnosed on not diagnosed at all, meaning they lose all entitlement to the support and services they require. Women are also more likely than men to have a disability or a condition misdiagnosed or left undiagnosed.

## What could the EU do to address this situation?

The EU should support Member States in making reforms to the way they conduct disability assessment and the support that follows it. The European Commission should urge Member States to make changes to their disability assessment practices through recommendations as part of the European Semester process. Suggested reforms could then be supported using Cohesion Funds or financing from the Recovery and Resilience Facility. Among the reforms we would suggest Member States looking at are the following:

### Reform how disability assessment is conducted:

* Adopt a holistic method for disability assessment that looks at a combination of impairment and functional considerations while also having a focus on the person’s support requirements and societal barriers.
* Provide opportunities for persons with disabilities to be part of their own assessment process. It should allow them to offer their insights and evaluations of their disability and their support needs. This could be done through a face-to-face meeting with the assessor or via a self-assessment that they complete.
* Improve the understanding of “hidden” or “invisible” disabilities, as well as rare conditions, of all professionals who are part of the disability assessment process to avoid misdiagnosis or absence of diagnosis. Professionals should also be better trained into the way different conditions and disabilities manifest themselves in women, who have a greater tendency to be misdiagnosed.
* Focus on reducing waiting times for people awaiting disability assessment and reduce excessive demands for reassessment. Continued assessment should be done in a reasonable and measured way and only when justified so as not to place the person with disability under unnecessary stress.
* Involve persons with disabilities and their representative organisations in developing and changing the systems and processes of disability assessment.

### Reform the way support is offered following disability assessment:

* Invest in providing disability allowance that is sufficient for persons with disabilities to live in a safe and dignified way and avoid falling below the poverty line.
* Investment should go not only to persons with disabilities directly, but also to strengthening accessible services that they can use. These might in some cases be disability-specific services used only by persons with disabilities, and in other cases be general public services that need further investment to be accessible to everyone (including public transport services).
* Facilitate entry to work by offering person-centred and flexible support to persons with disabilities to enable them to take up work. Persons with disabilities should not lose their entitlement to future disability allocations if they have been in work. When in employment, persons should be permitted to continue receiving disability allowances needed to compensate extra disability-related costs.
* Do not push persons with disability into employment by reducing disability allowance, using so-called “incentives to work”.
* Ensure that public funds are available to contribute to covering disability-related costs.

# Document credits

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1. <https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=URISERV:ai0020> [↑](#footnote-ref-1)
2. <https://ec.europa.eu/eurostat/documents/2995521/14233881/2-02022022-AP-EN.pdf/ae797c3b-899c-8d61-afd6-a08eb5f086f6> [↑](#footnote-ref-2)
3. http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=hlth\_dm060&lang=en: This dataset shows six different figures: the percentage of households making ends meet with great difficulty, with difficulty, with some difficulty, fairly easily, easily, and very easily. The total of all these options equals 100%. Here we take the data for households containing a person with either "severe" of "some" limitations, and combine the percentages of respondents making ends meet with "great difficulty", "difficulty" or "some difficulty". [↑](#footnote-ref-3)
4. Idem [↑](#footnote-ref-4)
5. <https://www.politico.eu/article/europe-gas-price-surge-energy-crisis/> [↑](#footnote-ref-5)
6. Pp 23 <https://mcusercontent.com/865a5bbea1086c57a41cc876d/files/ad60807b-a923-4a7e-ac84-559c4a5212a8/EDF_HR_Report_final_tagged_interactive_v2_accessible.pdf> [↑](#footnote-ref-6)
7. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> [↑](#footnote-ref-7)
8. Available at: <https://europa.eu/euandme/passion/work-and-live-abroad_en> [↑](#footnote-ref-8)
9. Available at : <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A12012M%2FTXT> [↑](#footnote-ref-9)
10. Available at: <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex:12012E/TXT> [↑](#footnote-ref-10)
11. <https://ec.europa.eu/commission/presscorner/detail/en/ip_21_810> [↑](#footnote-ref-11)
12. <https://ec.europa.eu/eurostat/databrowser/view/HLTH_DLM200/default/table?lang=en&category=hlth.hlth_dsb.hlth_dsb_lm.hlth_dsb_lm_> [↑](#footnote-ref-12)
13. Antón, J.I., Braña. F.J. and Muñoz de Bustillo, R. (2014). An analysis of the cost

of disability across Europe using the standard of living approach. Available at:

[https://link.springer.com/content/pdf/10.1007%2Fs13209-016-0146-5.pdf](https://link.springer.com/content/pdf/10.1007/s13209-016-0146-5.pdf) [↑](#footnote-ref-13)
14. Pp 56 <https://mcusercontent.com/865a5bbea1086c57a41cc876d/files/ad60807b-a923-4a7e-ac84-559c4a5212a8/EDF_HR_Report_final_tagged_interactive_v2_accessible.pdf> [↑](#footnote-ref-14)
15. <https://ec.europa.eu/info/sites/default/files/2020-european-semester-joint-employment-report_en.pdf> [↑](#footnote-ref-15)
16. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-23-respect-for-home-and-the-family.html> [↑](#footnote-ref-16)