# EDF Alternative report for the second review of the EU by the CRPD Committee

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Submission for the List of Issues Prior to Reporting on the EU



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### **European Disability Forum**

The European Disability Forum (EDF) is an umbrella organisation of persons with disabilities that defends the interests of over 100 million persons with disabilities in Europe.

We are an independent non-governmental organisation that brings together representative organisations of persons with disabilities (DPOs) from across Europe. We currently have 101 members, including European-wide organisations representing various disability groups, and national council of persons with disabilities. Taking in account our members' memberships, we gather over 3000 organisations.

We are run by persons with disabilities and their families. We are a strong united voice of persons with disabilities in Europe.

### **Executive summary**

The EDF alternative report examines the European Union's (EU) implementation of the Convention on the Rights of Persons with Disabilities (hereinafter referred to as "CRPD" or "the Convention") since its first review by the United Nations (UN) Committee on the Rights of Persons with Disabilities (CRPD Committee) in 2015. The report is divided into two main parts: the first part analyses the implementation of the Convention in its policy work and the second part looks at the internal implementation of the Convention by the EU as a public administration. For each article, the report lists the main concerns and provides suggested questions to be addressed in the List of questions prior to reporting.

As an introductory remark, EDF's report highlights that while progress has been made by the EU, for example with the adoption of the European Accessibility Act, of a new 10-year strategy on disability rights and the EU ratification of the Marrakesh Treaty,<sup>1</sup> the overall purpose of the CRPD - to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities - is not yet realised.

### EDF's main concerns are as follows:

- Legal harmonisation with the CRPD: The Commission has not taken steps to ensure legal harmonisation with the CRPD. The review of existing legislation and policy has not taken place.
- 2. **Implementation and enforcement of EU legislation**: Existing EU legislation relating to the rights of persons with disabilities, such as the Employment Equality Directive, the EU package of Passenger Rights (regulations related to the rights of passengers by air, rail, coach and bus, and by sea), the Rail Accessibility Regulation,<sup>2</sup> the Audiovisual Media Services Directive,<sup>3</sup> and the Directive on Victims' Rights, lack effective implementation and enforcement.

<sup>1</sup> Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired or Otherwise Print Disabled

<sup>&</sup>lt;sup>2</sup> Commission Regulation (EU) No 1300/2014 of 18 November 2014 on the technical specifications for interoperability relating to accessibility of the Union's rail system for persons with disabilities and persons with reduced mobility

<sup>&</sup>lt;sup>3</sup> Directive (EU) 2018/1808 of the European Parliament and of the Council of 14 November 2018 amending Directive 2010/13/EU on the coordination of certain provisions laid down by law, regulation or administrative action in Member States concerning the provision of audiovisual media services (Audiovisual Media Services Directive) in view of changing market realities

- 3. Consultation and involvement of persons with disabilities: There is no clearly structured or documented process for the consultation of persons with disabilities and their representative organisations. Consultation continues to be ad hoc across all institutions. In some institutions and bodies, such as the Council, there is no consultation or minimal involvement. Additionally, the digital tools for public consultations are not accessible, nor provided in accessible and easy to read formats.
- 4. Protection against discrimination: EU anti-discrimination legislation is inconsistent in its scope and creates a hierarchy between the different grounds for discrimination. Persons with disabilities are only protected against discrimination in employment and vocational training. EU laws do not cover multiple and intersectional forms of discrimination and discrimination by association. The EU has not yet adopted a horizontal antidiscrimination legislation, since the 2008 proposal for an Equal Treatment Directive is stalled in the Council. There is no legal requirement for Equality Bodies to protect victims of discrimination across the EU.
- 5. **Women with disabilities**: EU laws and policies on gender equality and on disability do not fully take into consideration the rights and needs of women and girls with disabilities. They continue to face higher risk of violence than other women, more discrimination than men with disabilities in access to employment, education, and health, and they are exposed to human rights abuses such as forced sterilisation.
- 6. **Accessibility:** Despite recent progress in EU accessibility law<sup>4</sup>, persons with disabilities still do not have equal access to the built environment, transport, digital technologies, information and communication, and services. The lack of availability of affordable assistive technologies and the lack of information and communication in accessible formats (including sign language) limit the active and full participation of many persons with disabilities in the internal market of the EU. Moreover, it deprives them of one of the basic freedoms under EU Treaties: the freedom of movement. Recent legislative proposals in the digital domain regulating digital services and platforms, as well as artificial intelligence, prove that there is a lack of mainstreaming accessibility requirements in the digital sector.<sup>5</sup>
- 7. Civil protection, humanitarian and climate actions: Persons with disabilities across Europe and globally are still being disproportionately impacted by conflict and by natural events such as the COVID-19 pandemic, flooding and heatwaves. Recent years have seen improvement in international and EU policies in this field, but these frameworks are not yet being implemented, and progress is slowed down by a lack of cohesion and collaboration between bodies responsible for disability inclusion in humanitarian action, civil protection, disaster risk reduction, climate action and refugee policies. In addition, the EU's climate goals and policies do not focus sufficiently on the social aspects of sustainability and Disaster Risk Reduction. Neither mitigation nor adaptation planning take persons with disabilities sufficiently into account.

Directive, European Accessibility Act. <sup>5</sup> Also, accessibility in the EU is often

<sup>&</sup>lt;sup>4</sup> Web Accessibility Directive, European Electronic Communications Code, Audiovisual Media Services Directive, European Accessibility Act.

<sup>&</sup>lt;sup>5</sup> Also, accessibility in the EU is often understood as the accessibility of physical and virtual environments only, which means that accessibility of information and communication, especially in national sign languages, in the EU is often not addressed. Even though all the EU Member States have now recognised their national sign languages, the EU does not recognise the national sign languages as part of the multilingualism of the EU and does not promote their use.

- 8. **Denial of legal capacity**: Persons with disabilities, whose legal capacity has been denied or limited, are unable to enjoy and exercise an array of rights that come from EU law, such as the right to a fair trial, to decide where to live, to sign employment or commercial contracts, to make financial transactions, privacy, or to vote and stand for election in European and local elections.
- 9. Access to justice: The justice system at EU and national level is not fully accessible to persons with disabilities. Whether as victims, witnesses, suspect or accused, or staff, persons with disabilities face many barriers in exercising their rights. EU legislation addressing the justice system is not implemented in a way that is accessible for persons with disabilities and guarantee their rights to a fair trial. The EU Justice Scoreboard does not evaluate the compliance of national justice system with the CRPD.
- 10. Violence: Persons with disabilities, in particular children and women with disabilities, persons with intellectual disabilities and autism, older persons with disabilities and persons with disabilities living in closed settings, are still at higher risk of violence and abuse than other people. The EU has not ratified the Istanbul Convention on violence against women and domestic violence<sup>6</sup> or adopted other measures to combat violence.
- 11. Freedom of movement: Persons with disabilities cannot transfer their social security allowances from their Member State of origin when they move to a different Member State temporarily. In practice, this denies persons with disabilities who hold the citizenship of one of the 27 EU Member States, as well as Norway, Iceland, Lichtenstein, and Switzerland, of the right they hold under the EU treaties to live and work freely throughout the EU. Even when they move to a different Member State permanently, they often have difficulties in getting their disability status recognised and face additional bureaucratic burdens. This also impact young people taking part in exchange programmes.
- 12. **Use of EU funds and independent living**: Some Member States have used Structural Funds to maintain and promote institutional care, rather than developing community-based alternatives in line with the CRPD and investing in opportunities for personal assistance. This results in the continuation of human rights violations in institutions within the European Union. The EU also fails to collect data on people living in institutions, since EU-level data collection focuses on people living in "households" which does not include institutional settings. This means that the EU has no clear understanding of how many people live in these kinds of settings, nor a means to measure the progress in the transition away from institutionalisation that EU funds are supposed to facilitate.
- 13. Health: The EU fails to consider the rights and needs of persons with disabilities in its health policies, including in actions taken during the COVID-19 pandemic and in its European Beating Cancer Plan from prevention, to screening and treatment. Only 14 EU Member States prohibit disability-based discrimination and have a requirement of reasonable accommodation in access to healthcare.
- 14. **Participation in political and public life:** The EU has not aligned the 1976 Electoral Law with the CRPD. There are 14 Member States in which persons with disabilities under total or partial guardianship are denied of their right to vote in the European

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<sup>&</sup>lt;sup>6</sup> Council of Europe Convention on preventing and combating violence against women and domestic violence

- elections (approximately 400,000 people). In only 7 Member States all persons with disabilities are entitled to stand as candidates to the European Parliament elections. And many accessibility barriers prevent millions of persons with disabilities from participating in the elections. Likewise, democratic exercises such as the Conference on the Future of Europe are inaccessible to persons with disabilities.<sup>7</sup>
- 15. **Data collection**: Very limited reliable data on persons with disabilities is available at EU level. For example, there is almost no information on persons with disabilities in institutions, women and girls with disabilities, LGBTIQ+ persons with disabilities, and persons with disabilities from ethnic minorities such as Roma and Travellers with disabilities. Data is also not disaggregated by different types of disability, gender and age, and data collection and surveys may not be accessible to all persons with disabilities. A precise assessment of the situation of persons with disabilities across Europe is therefore not possible (including for instance in relation to situation of emergency).
- 16. **EU** in the World: Although the EU is the largest donor in the field of international cooperation, it has not yet undertaken all appropriate measures to enhance EU disability-inclusive development policies and programmes. The perspectives and voices of persons with disabilities are not included in EU global policies.
- 17. **CRPD Implementation and monitoring**: The EU has neither created a CRPD unit, nominated focal points in all institutions, agencies and bodies nor established an inter-institutional mechanism for the coordination of the implementation of the Convention between the Commission, the Parliament, and the Council.

### Context

The European Union (EU) is a unique economic and political union between <u>27 EU countries</u> that together cover much of the European continent.

The EU was the first regional organisation to ratify the UN Convention on the Rights of Persons with Disabilities in 2010. It was reviewed for the first time by the UN Committee on the Rights of Persons with Disabilities in 2015. Since then, the EU was marked by several events:

- Since March 2018, all the EU member states have ratified the CRPD.
- On 31 January 2020, the United Kingdom left the EU. Prior to that date there were 28 member states.
- Since 2015, two consecutive colleges of Commissioners led the work of the
  European Commission (the executive body of the EU). The current college of
  Commissioners is led by President of the European Commission, Mrs. Ursula von der
  Leyen, for a 5-years term (2019-2024). It is composed of 27 Commissioners from
  each EU member states who are assigned responsibility for specific policy areas, for
  instance: equality, justice, jobs, and social rights, health, and food safety, democracy,
  and demography, values, and transparency. The implementation of the CRPD is
  under the mandate of the Commissioner for Equality, Ms. Helena Dalli.

<sup>&</sup>lt;sup>7</sup> EDF, <u>The platform of the Conference on the Future of Europe must fix its accessibility problems</u> (September 2021)

### Methodology

This alternative report was prepared by the Secretariat of the European Disability Forum in close cooperation with, and guidance from its Executive Committee, Board and Members. EDF Youth and Women's Committees were also closely involved in the process. Information was collected through desk research and consultation with EDF national and European members between September 2021 and January 2022.

Substantive contributions were received from the following organisations: AGE Platform, Alzheimer Europe, Autism Europe, the Belgian Disability Forum, COFACE Families Europe, Disabled People's Organisation Denmark, European Blind Union, European Deafblind Union, European Federation of Hard of Hearing People, European Network of Equality Bodies (Equinet), European Women's Lobby, European Union of the Deaf, Inclusion Europe, Mental Health Europe and the National Confederation of Disabled People (Greece).

Part 2 of the report was informed thanks to the contribution of the Disability Support Groups of the EU institutions and bodies, as well as through personal testimonials shared by employees and former employees of the Institutions, and parents of children registered or formerly registered in the European schools.

### **Abbreviations and acronyms**

CRPD	Convention on the Rights of Persons with Disabilities
DG	Directorate-General (of the European Commission)
DPO	Disabled People Organisation / Organisation of Persons with Disabilities
EU	European Union
FRA	Fundamental Rights Agency
UN	United Nations

### **Glossary**

**Council of the European Union**: the institution representing the governments of EU Member States and where national ministers from each EU country meet to adopt laws in agreement with the European Parliament, and coordinate policies.

**Council of Europe**: an international organisation founded in 1949 with the aim to uphold human rights, democracy, and the rule of law in Europe. It has 47 member states which have ratified the European Convention of Human Rights and are therefore overseen by the European Court of Human Rights, an entity independent of the European Union.

**(EU) Directive**: legislative act that sets out goals that all EU countries must achieve. The directive must be transposed at national level. It means that this is up to the individual countries to decide based on their own laws how to reach these goals (e.g., it can be by amending existing national laws or introducing new ones).

**European Commission**: the EU's politically independent executive arm. Its core responsibilities include proposing EU laws and policies and monitoring their implementation.

**European Council**: the body that brings together EU leaders to set the EU's political agenda. It represents the highest level of political cooperation between EU countries. It is

composed of the heads of state or government of all EU countries, the European Council President, and the European Commission President.

**European Parliament**: the elected parliamentary institution of the European Union which has the role to adopt EU legislation in agreement with the Council of the European Union.

**European Semester**: the framework for integrated surveillance and coordination of economic and employment policies across the European Union. Since its introduction in 2011, it has become a well-established forum for discussing EU countries' fiscal, economic and employment policy challenges under a common annual timeline.

**Member State (of the European Union)**: the EU consists of 27 countries, also called Member States. Each Member State is party to the founding treaties of the Union, and thereby subject to the privileges and obligations of membership. Unlike members of most international organisations, the Member States of the EU are subjected to binding laws.

**(Legal) Provision**: it is a clause, an article, in a legal instrument, a law, etc., providing for a particular matter.

**(EU) Regulation**: legislative acts that must be applied in its entirety across all EU countries (binding legislative act). Once adopted, the regulation automatically becomes national law (unlike the EU Directive).

**Resolution**: text adopted by the European Parliament in its plenary session and through which the Parliament expresses its position on a given area.

**Structural and Investments funds**: EU funding that aim to support economic, social, and territorial cohesion and deliver the overarching policy EU objectives. Three main funds directly impact the living conditions of persons with disabilities: the European Regional Development Fund (ERDF), the European Social Fund (ESF), and the Cohesion Fund (CF).

**Transposition**: process by which the EU's Member States give force to a directive by passing appropriate implementation measures. Transposition is done by either primary or secondary legislation.

# Part 1: Review of general provisions of the UN Convention on the Rights of Persons with Disabilities

**Articles 1 to 4: General principles and obligations Ratification of the Optional Protocol** 

The EU has not ratified the Optional Protocol of the CRPD. Within its membership, 21 member states have ratified the protocol.<sup>8</sup>

### Suggested question:

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<sup>&</sup>lt;sup>8</sup> Bulgaria, Czechia, Ireland, the Netherlands, Poland, and Romania have not ratified the Optional Protocol.

 What are the measures and timeframe of the European Union to conclude the ratification of the Optional Protocol to the Convention?

### Legal harmonisation with the CRPD

The review of legislation and policy, and update of the **declaration of competences**<sup>9</sup> **and its list of instruments**<sup>10</sup> as recommended by the CRPD Committee have not been undertaken. The EU has not yet proposed a plan or strategy on how to ensure this legal harmonisation with the CRPD.

Examples of legislation or policy that should be repealed or revised are:

- Regulation 1107/2006 on Air Passengers' Rights for Persons with Disabilities still
  allows airlines to deny persons with disabilities boarding the plane if they are
  considered a "safety risk" which is not defined in the Regulation and often used
  arbitrarily and at the expense of the passenger.
- Regulation 1300/2014 on Technical Specifications for the Interoperability of the
   Union's Rail System for Persons with Disabilities ("TSI-PRM") concerns accessibility
   of rolling stock and stations but still allows in some cases for inaccessible trains to be
   manufactured and sold.

In addition to reviewing legislation and policies, it is also important that the EU reviews the **terminology** it uses in legislation, publications, and on its website. See under Article 8: Awareness raising

Finally, the **impact assessment guidelines**<sup>11</sup> of the Commission pre-dated the CRPD and did not adequately assess if policies are CRPD compliant. In November 2021, the European Commission published <u>"Better Regulations Guidelines" and a toolbox</u> that makes reference to persons with disabilities and accessibility. At the time of submission of this report, the impact of the guidelines was not yet reviewed.

Mainstreaming is not sufficiently ensured by the EU, an example being the EU's "Green Deal". All new legislation, initiatives, and programmes that result from the EU's "Green Deal" shall be in line with the CRPD and fully inclusive of persons with disabilities, including all procedures and platforms used for consultation and decision-making.

### Suggested questions:

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<sup>&</sup>lt;sup>9</sup> The EU Strategy for the rights of persons with disabilities 2021-2030 indicates that the "Commission will initiate work with the Council to update the EU declaration concerning the competence of the EU with regards to matters governed by the UNCRPD as recommended by the UNCRPD Committee in 2015." However, no specific timeframe is given to complete this work.

<sup>&</sup>lt;sup>10</sup> The list of instrument is an <u>appendix to the Council decision of 26 November 2009 concerning the conclusion</u>, by the European Community, of the <u>United Nations Convention on the Rights of Persons with Disabilities (2010/48/EC)</u>. It refers to Regulations and Directive relevant to persons with disabilities.

<sup>&</sup>lt;sup>11</sup> <u>Impact assessments</u> examine whether there is a need for EU action and analyse the possible impacts of available solutions. These are carried out during the preparation phase, before the Commission finalises a proposal for a new law. They provide evidence to inform and support the decision-making process.

- What is the intended timescale to conduct a review of EU legislation and policies affecting the lives of persons with disabilities and update the EU declaration of competences and its list of instruments accordingly?
- What practical initiative will the EU take to ensure legal harmonisation with the CRPD of all its existing and new laws, policies, and programmes?

### Strategies for the implementation of the CRPD

The previous 10-years European Disability Strategy ended in 2020. In March 2021, the European Commission adopted a new <u>Strategy for the Rights of Persons with Disabilities</u> <u>2021-2030</u> ("Disability Rights Strategy"), following consultations with organisations of persons with disabilities.

The Strategy is based on the CRPD and recalls the recommendations received by the EU from the CRPD Committee in 2015. However, while some actions are very concrete, with a clear timeframe; other objectives are more aspirational and must be further elaborated in the form of an action plan, giving dates for all actions to implement the Strategy in full. For example, the European Commission is planning to work with Member States to expand the scope of the mutual recognition of disability status in areas such as labour mobility and benefits related to conditions of service provision. But so far, no timeframe and resources have been established for this activity.

There is also a concern raised by some organisations that the Strategy, and the EU in general, <sup>12</sup> pay little to no attention to disability as a result of cognitive or neurological conditions, such as dementia and Alzheimer.

### Suggested question:

 What are the measures foreseen by the Commission to elaborate a more detailed action plan on the implementation of the European Disability Rights Strategy, including intermediate targets for steps towards adoption of legislation and policies to foster the implementation of the CRPD?

# Active involvement and participation of representative organisations of persons with disabilities

There are no legal provisions establishing inclusive and accessible procedures and mechanisms for the involvement of persons with disabilities and their representative organisations, across all disability constituencies, in the development and implementation of EU legislation and policies to implement the Convention. Consultation continues to be ad hoc across all EU institutions.

In particular, organisations of persons with disabilities are not consulted and involved in the work of the Council of the European Union. This creates huge problems in the legislative process: even though Commission and Parliament are often willing to include CRPD-conform changes in legislation, the Council often blocks (for example with the proposed Horizontal Non-Discrimination Directive; or with the revision of the Rail Passengers' Rights Regulation).

<sup>&</sup>lt;sup>12</sup> For example, the FRA carriers out research and reports on disability more broadly, however, it does little on specific areas such as cognitive disabilities, e.g., dementia.

Since organisations of persons with disabilities do not have sufficient access to information about Council proceedings and decisions, decisions are taken de facto behind closed doors, against the rights of persons with disabilities.

In particular, the disability movement advocate for:

- Involvement in the European Commission's Inter-Service Group on Disability and the Council of the European Union's <u>Working Groups'</u> meetings on any file that directly concerns persons with disabilities such as transport, ICT, social policy, human rights, etc.
- Access to timely information on the work of the Council of the European Union, such as Council Working Groups' meetings, including agendas, preparatory documents, minutes, and recording of meetings in accessible formats.

More information about inaccessibility of consultation is available under par 2 - **Article 9**It is also important to note that the EU should provide more accommodating and suitable timeframes, especially when seeking to involve disability organisations to allow for more meaningful involvement. Some consultations are organised under very short timeframes and/or in holidays period during which not all stakeholders have the capacity to participate meaningfully, including by involving their constituency.

### Suggested question:

 What steps will the EU take to set up a structured dialogue with an independent budget line and sufficient funding for coordination among EU institutions, agencies, and bodies with persons with disabilities in all their diversity and their representative organisations?

### Implementation of EU legislation

Existing EU legislation affecting the rights of persons with disabilities, such as the Employment Equality Directive, the EU package of Passenger Rights, the Victims' Rights Directive, lack effective implementation and enforcement.

### For example:

- The Passengers' Rights Regulations are a very useful tool but knowledge among persons with disabilities about their rights are limited and transport providers often ignore the provisions. National Enforcement Bodies are not equipped with the necessary resources to follow up on individual complaints. There is also an element of inequality: while passengers can claim financial compensation for a flight that was cancelled, persons with disabilities cannot claim compensation if they have been denied boarding because of their disability or if their assistive technologies have been damaged. Furthermore, the complaints process is not always clear and often not accessible, which deters passengers from lodging complaints and claiming their rights.
- Article 5 of the Employment Equality Directive on 'reasonable accommodation for disabled persons' has an inconsistent and insufficient implementation across the EU.

Many EU member states<sup>13</sup> lack a definition of "reasonable accommodation" in its legislation in line with the Directive and the CRPD. There is a poor understanding of what reasonable accommodation in the workplace means, and it is rarely applied.

The Victims' Rights Directive contains articles on interpretation and accessibility (for example accessibility of shelters) but there is very limited adequate transposition and implementation in EU Member States.14

It is also not clear which measures the European Commission takes to ensure the adequate transposition and implementation of the EU legislation in its member states, including from a disability perspective.

### Suggested question:

- What steps will the EU take to ensure effective implementation and enforcement of current and upcoming EU legislations relevant to persons with disabilities and their compliance with the CRPD?
- How does the European Commission plan to better monitor the implementation and transposition of EU legislation on disability through the EU Semester process and to make disability issues more present in the Country Specific Recommendations presented to the Member States?
- How will the EU make better use of enforcement tools such as infringement procedures?

### **Article 5: Equality and non-discrimination**

Persons with disabilities living in the EU continue to face discrimination, including denial of reasonable accommodation, harassment<sup>15</sup> and multiple and intersectional forms of discrimination in all areas of their lives. Despite this situation, the EU has failed to adopt strong and effective actions to protect persons with disabilities against discrimination in all areas of life.

Under EU law, persons with disabilities are only protected against discrimination in the field of employment and vocational training.<sup>16</sup> Existing legislation includes an obligation to provide reasonable accommodation for employers but does not explicitly recognise the denial of reasonable accommodation as a form of discrimination.<sup>17</sup> In addition it does not explicitly recognise discrimination by association<sup>18</sup> and does neither recognise nor address

<sup>&</sup>lt;sup>13</sup> For example, in Austria, Bulgaria, Denmark, Estonia, Germany, Italy, Latvia, Luxembourg, Portugal, Sweden. These are findings from EDF's 2019 European Human Rights report on equality.

<sup>&</sup>lt;sup>14</sup> See for instance the findings of the <u>ARVID project on Advancing Access to Rights under Victims'</u> Directive for Persons with Disabilities.

<sup>&</sup>lt;sup>15</sup> According to data published by the Fundamental Rights Agency of the European Union (FRA), 50% of persons with disabilities have reported being harassed over a 5-year period, comparing to 37% of persons without disabilities. See FRA, Fundamental Rights Survey: CRIME, SAFETY AND VICTIMS' RIGHTS (2021), page 22.

<sup>&</sup>lt;sup>16</sup> Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation

<sup>&</sup>lt;sup>17</sup> See article 2 "Concept of discrimination" of the directive.

<sup>&</sup>lt;sup>18</sup> However, the European Court of Justice hold in Case-303/06 Coleman v. Attridge Law stated that the directive applies to direct discrimination or harassment by association. The jurisprudence did not explicitly recognise indirect discrimination by association. In addition, the judgment in Coleman v.

multiple and intersectional forms of discrimination. Consequently, some groups of persons with disabilities are facing higher degree of discrimination with no or limited access to legal remedy. This affects for instance, women with disabilities, young and older persons with disabilities, migrants and refugees with disabilities, persons with disabilities from ethnic minorities, including Roma with disabilities, and LGBTIQ+ persons with disabilities.

Contrary to disability-based discrimination, discrimination on the grounds of sex and race, is prohibited in employment and in other areas of life, such as social protection including social security and healthcare, social advantage, education, and access to and supply of goods and services. Therefore, **EU** anti-discrimination legislation remains inconsistent in its scope and creates a hierarchy between the different grounds for discrimination.

For more than 10 years, the EU has been discussing a proposed horizontal equal treatment directive covering discrimination on the grounds of disability, age, religion or belief, and sexual orientation in the areas of social protection, healthcare, (re)habitation, education and the provision of goods and service. Resistance still remains from the member states in the Council of the EU to adopt this piece of legislation. The changes made to the proposed file during the recent negotiation process are especially concerning regarding the removal of accessibility and exemptions to the provision of reasonable accommodation for persons with disabilities, as well as multiple and intersectional discrimination.<sup>20</sup>

Further, the Directive would extend the mandate of Equality Bodies<sup>21</sup> to work on the ground of disability across the EU. So far, there is no legal requirement for Equality Bodies to protect victims of discrimination across the EU.<sup>22</sup>

In 2020 and 2021, the European Commission adopted a series of policy initiatives and strategies that could contribute to a better inclusion of disadvantaged groups, namely the Gender Equality Strategy 2020-2025, the LGBTIQ Equality Strategy 2020-2025, the EU antiracism action plan 2020-2025, the Roma strategic framework for equality, inclusion and participation 2020-2030, the Action plan on the integration and inclusion 2021-2027, and the Green paper on Ageing. A EU Youth Strategy for 2019-2027 with 11 European Youth Goals was adopted in 2018. Disability-based discrimination and persons with disabilities are mentioned in most of these initiatives.<sup>23</sup> However, without concrete actions and a disability

Attridge did not recognise a right to reasonable accommodation because of an association with a person with disabilities.

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<sup>&</sup>lt;sup>19</sup> Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation; see <a href="Interinstitutional File: 2008/0140(COD">Interinstitutional File: 2008/0140(COD)</a>.

<sup>&</sup>lt;sup>20</sup> Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, <u>Interinstitutional File:</u> 2008/0140(CNS) (May 2021).

<sup>&</sup>lt;sup>21</sup> Equality bodies are national public institutions set up across Europe to promote equality for all and tackle discrimination. Find more information on the website of the <u>European Network of Equality</u> Bodies.

<sup>&</sup>lt;sup>22</sup> Currently, some Member States have voluntarily extended the mandate of Equality Bodies, but some have not, implying that persons with disabilities do not enjoy the same protection across the EU. The European Commission will make a proposal regarding standards for these bodies in 2022, which should address this *lacuna*, giving victims of discrimination based on disability the same rights as other right holders across the EU.

<sup>&</sup>lt;sup>23</sup> The EU Youth Strategy failed to include young persons with disabilities.

focal point in charge of monitoring and contributing to the implementation of these initiatives, it is not certain to which extent persons with disabilities facing multiple and intersectional forms of discrimination<sup>24</sup> will benefit from them.

Another important concern relates to the increasing use and impact of artificial intelligence (AI) on disadvantaged groups in the European Union. In spring 2021, the European Commission published a legislative proposal to regulate artificial intelligence in the EU. Civil society actors, including EDF, have raised numerous concerns about risks of AI on fundamental rights and widening inequalities, and the huge shortcomings of the proposal to address harmful impacts of AI, including ensuring effective prohibition against biometric mass surveillance by law enforcement and private actors, predictive policing, emotion recognition, use of AI for determining access to education and employment, enjoyment of public and private essential services and benefits, migration, asylum and border control.<sup>25</sup> AI may also have a negative impact on children and women, including children and women with disabilities.<sup>26</sup>

### Suggested questions:

- Which measures will the EU take to ensure persons with disabilities are protected against discrimination in all areas of life, including areas of social protection, healthcare, rehabilitation, education and the provision of goods and services, such as housing, transport, and insurance, as well as ensuring Equality Bodies have a mandate to work on disability across the EU?
- Which additional steps will the EU take to recognise and condemn the denial of reasonable accommodation as a form of discrimination, and combat and condemn multiple and intersectional forms of discrimination and discrimination by association?
- How is the EU planning to address the potential discriminatory impact of artificial intelligence on persons with disabilities?

### Article 6: Women with disabilities

Women with disabilities constitute 16% of the total population of women in the EU and 60% of the overall population of 100 million persons with disabilities.<sup>27</sup>

legislation, will be grounds those provisions would also be applied.

<sup>&</sup>lt;sup>24</sup> The above-mentioned horizontal equal treatment Directive proposal incorporated provisions regarding intersectional and multiple discrimination. Nonetheless, given the lengthy negotiations in the Council, it remains not adopted. Further, concerns have been raised regarding the scope of application of the provisions, regarding whether gender and race, protected by other pieces of

<sup>&</sup>lt;sup>25</sup> See EDF position paper on the AI Regulation proposal; EDRi response to public consultation on AI Regulation proposal

<sup>&</sup>lt;sup>26</sup> See examples of discrimination provided in the alternative report, including in the education and employment areas. Issue of surveillance was also raised by some EDF's members. However, it's important to note that there is no data on the impact of AI use for people with disabilities and specifically for children and young people and women with disabilities who are often excluded of recent studies.

<sup>&</sup>lt;sup>27</sup> European Parliament <u>resolution of 29 November 2018 on the situation of women with disabilities</u> (2018/2685(RSP)), para. A.

In the last decade women with disabilities were invisible in EU's policies on gender equality and women's rights. The Gender Equality Strategy 2010-2015 and strategic engagement for gender equality 2016-2019 did not include the perspective of women with disabilities.

In March 2020, the new European Commission adopted a <u>Gender Equality Strategy for</u> 2020-2025 which encompasses some of the concerns of women with disabilities such as violence and harmful practices (e.g. forced sterilisation). However, women with disabilities are still invisible in the parts of the strategy on **work and employment**, **political participation**, and **leadership**. While there is more than 60 million of women with disabilities in Europe, they are still mostly considered as object of care or as victims and continue to face multiple and intersectional forms of discrimination in the areas of education, employment, health, and access to justice.

The 2021-2030 European Disability Rights Strategy mainstreams the gender perspective of in its different sections but lacks specific actions and measures on their issues such as regarding employment and political participation.

The EU has promised to ratify Council of Europe's Convention on preventing and combatting violence against women and domestic violence (Istanbul Convention). However, several member states have not ratified it yet at national level (namely: Bulgaria, Czech Republic, Hungary, Latvia, Lithuania, and Slovakia) and are also unwilling to agree to the EU's ratification. As the EU's accession to the Istanbul Convention remains blocked, in line with its new Gender Equality Strategy, the Commission organised consultations on gender based and domestic violence and announced that it will publish a proposal of a Directive on combatting violence in March 2022. EDF and other organisations of persons with disabilities were contacted to participate in public and targeted consultations. See Article 16 and 17.

The sexual and reproductive rights of girls and women with disabilities are not sufficiently taken into account in EU Member States: they are most often treated for their disability, but have difficulties in accessing care and information, especially on contraception, abortion, sexual education, which leads to a lack of prevention, in particular gynaecological smears, mammography. Women in institutions are poorly included in prevention policies. They are sometimes subjected to forced and non-personalised contraception. Finally, they are often dissuaded from becoming mothers. The European Commission has not taken specific actions to ensure the sexual and reproductive health and rights of women and girls with disabilities, including in its gender and health policies. **See also Article 25.** 

Women and girls with disabilities are not systematically reached in international cooperation. At the international level, the EU and the UN embarked on a global, multi-year initiative focused on eliminating all forms of violence against women and girls - the <a href="Spotlight Initiative">Spotlight Initiative</a>. The EU invested initially 500 million of Euros, but women and girls with disabilities are not specifically included.

The new <u>Gender Equality Action Plan</u> promotes gender equality and women's empowerment through all EU's external action from 2021-2025 (GAP III). It includes the perspectives of women and girls with disabilities and intersectionality as a core principle. GAP III country level implementation plans however do not systematically include an intersectional approach.

Country level consultations with civil society on the GAP III implementation often do not include the voices of women and girls with disabilities, including through providing accessibility and reasonable accommodation, and by involving representative organisations of persons with disabilities.

### Suggested questions:

- How will the EU ensure that the perspective of women and girls with disabilities are included in the implementation and evaluation of its Disability Rights Strategy 2021-2030 and Gender Equality Strategy 2020-2025, including in actions targeting access to work and employment, political participation, and leadership and in the work of the European Institute on Gender Equality (EIGE)?
- What actions is the EU taking to accede to the Council of Europe's Convention on preventing and combatting violence against women and domestic violence?
- What steps will the EU and the EU delegations take to ensure that women and girls with disabilities are systematically included and counted in all EU's work, including its global work and in partner countries?

### **Article 7: Children with disabilities**

There are around 68 million children below the age of 15 in the EU<sup>28</sup> but there is very limited data on children with disabilities. According to Eurostat, about 5% of EU families with children had a child or children with disabilities<sup>29</sup> and 9.4% of girls and young women and 7.5% of boys and young men (ages 16-24) had a disability.<sup>30</sup>

Despite the disproportionate risk they face, children with disabilities are given little to no consideration in national or European child rights legislation and/or when they are included in legislation, those are not effectively implemented. In many EU countries, children with disabilities are institutionalised, segregated in special schools and are victims of violence and abuse, in and outside their family setting (including incest).<sup>31</sup>

In 2021, the EU adopted its new <u>Strategy on the Rights of the Child</u>. It better acknowledges the rights of children with disabilities than the 2011-14 Agenda.<sup>32</sup> It is explicitly mentioned that the Strategy is anchored to the CRPD. It mentions the right of children with disabilities to live with their families and in a community, the need for specific responses to their mental and physical health, inclusive education and support for completing education, as well as the importance of accessible ICT and assistive technology.

<sup>29</sup> ilc hch13, 2017

<sup>&</sup>lt;sup>28</sup> Eurostat, 2020

<sup>&</sup>lt;sup>30</sup> EU-SILC, 2017

<sup>&</sup>lt;sup>31</sup> See for example in France: La Dépêche, <u>#Incestehandicap : les enfants handicapés victimes</u> <u>d'inceste, un sujet encore tabou qui manque de témoignages</u> (March 2021).

<sup>&</sup>lt;sup>32</sup> The 2011-2014 EU Agenda for the Rights of the Child failed to acknowledge the rights of children with disabilities. Except for a reference acknowledging that they are more exposed to violence and more at risk of seeing their rights violated, no actions directly concerning them were included in this now outdated Agenda.

In June 2021, as part of this overall Strategy, the EU also adopted its Renewed Child Guarantee for Vulnerable Children (or Child Guarantee), which aims to prevent and combat social exclusion by guaranteeing the access of children in need to a set of key services including early childhood education and care, education (including school-based activities), healthcare, nutrition and housing. The Child Guarantee lacks a strong commitment to end the institutionalisation of children across the EU. It is a missed opportunity and a particularly pressing issue for children with disabilities who are more likely to be institutionalised, and to remain in institutions on a long-term or permanent basis.

Participation and inclusion of the perspectives of children in EU policies is at its very early stages and is not systematic. "Children in vulnerable situations have fewer opportunities to contribute to decision making and the most marginalised and excluded children [such as children with disabilities] have even fewer opportunities to participate in decision making processes."<sup>33</sup>

In addition, children with disabilities are often excluded from events organised by the European Commission. The annual European Forum on the rights of the child is not accessible and rarely includes children with disabilities as speakers.

### Suggested questions:

- How will the EU ensure that the perspective of girls and boys with disabilities are included in the design, implementation and review/evaluation of its Child Rights Strategy and Child Guarantee for Vulnerable Children, in particular in regards to a health care and (re)habitation, mainstream education, technical and vocation education and training, preparation for the world of work, ICT/digital age, recreational opportunities, sport, and protection from violence, as well as in the work of the EU Agency for Fundamental Rights?
- How will the EU ensure meaningful consultations of children with disabilities and of their representative organisations regarding decisions affecting their lives, including in the annual European Forum on the rights of the child?

### **Article 8: Awareness raising**

The EU has undertaken limited awareness raising on the CRPD and the human rights-based approach to persons with disabilities. While some annual events such as the European Day of Persons with Disabilities conference, the Access City Award (rewarding accessible cities), and Work Forum on implementation of the CRPD, are welcomed, they only reach out to a limited number of participants (1 to 2 people per representative organisation of persons with disabilities per member state can attend each event). Knowledge on the CRPD and EU's obligations to implement it, are very limited on the ground.

In general, the EU fails to include persons with disabilities in most campaigns that concern them. Specific groups of persons with disabilities, including women and girls with disabilities,

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<sup>&</sup>lt;sup>33</sup> Joint position paper on a Comprehensive Child Rights Strategy co-signed by 40 international and European co-signatories, July 2020.

older persons with disabilities, young persons with disabilities and people with intellectual, psychosocial disabilities or autism are often excluded or not represented in awareness-raising campaigns and initiatives. Campaigns that are not specifically about persons with disabilities, but on issues that disproportionately impact persons with disabilities, do not involve their specific issues. An example was the crisis communication around COVID-19 response. People with disabilities and disability rights are also not visible in key research programmes and funding advertised by the European Commission. For example, the "EU Missions" aimed to tackle big challenges in health, climate and the environment, and to achieve ambitious and inspiring goals in these areas, do not include persons with disabilities.

In addition, the EU continues to use language that is not compliant with the CRPD. For instance, a summary of legislation on "Judicial co-operation in criminal matters: mutual recognition of final decisions in criminal matters" uses the term "mentally disabled."<sup>35</sup> The Statistical Classification of Economic Activities in the European Community of the Eurostat Reference and Management of Nomenclatures include concepts, such as "the disabled", and "mental retardation". In consumer affairs, persons with disabilities are often called "vulnerable groups" while in the context of EU transport policy the term most commonly used is "persons with reduced mobility". The latter also includes other disabilities in its definition but can be confusing at first sight and is, in fact, much broader.

The European Commission also fails to sufficiently include persons with disabilities in is country specific recommendations part of the "European Semester". <sup>36</sup> While the Country Reports, which are much broader in scope, often mention the issues faced by persons with disabilities, the Country-Specific Recommendations very rarely ever ask the Member States to take specific action to rectify the situation persons with disabilities face. <sup>37</sup> The European Semester Process has therefore shown itself to be under-ambitious in calling for an improvement to the realities of persons with disabilities in the EU. <sup>38</sup>

### Suggested questions:

• How will the EU develop comprehensive and accessible campaigns to raise awareness about the CRPD and ensure it uses CRPD compliant terminology when

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<sup>&</sup>lt;sup>34</sup> The COVID-19 crisis has left many persons with disabilities excluded and with lack of information, in particular deafblind people and persons living in institution. The reason for that is their hardened access to information without the adequate support (interpreters, personal assistants, and support persons – limited access due to the COVID-19 measures).

<sup>&</sup>lt;sup>35</sup> Commission communication to the Council and the European Parliament: Mutual recognition of final decisions in criminal matters [COM(2000) 495 final - not published in the Official Journal]; Summary <sup>36</sup> Each year, in a process known as the "European Semester", the European Commission delivers an analysis of socio-economic issues that need to be addressed in each EU member state (known as the Country Reports) and then subsequently delivers another document giving direct recommendations for how each Member State should act to improve this (called the Country-Specific Recommendations). <sup>37</sup> One of the exceptions in recent years has been regarding the Country Specific Recommendations to Latvia, where recommendations were given to improve social protection for persons with disabilities in the country, but similar recommendations should arguably have been delivered to other Member States.

<sup>&</sup>lt;sup>38</sup> In addition, it does not tackle all problematic subjects, such as legal capacity which could be in the recommendations as legal capacity is restricted in many member states and makes the right to vote or be elected impossible for certain people with disabilities.

referring to persons with disabilities? What other measures will it take to combat prejudice against persons with disabilities, including the most marginalised groups?

 How will the EU ensure the inclusion of disability rights and the close involvement of representative organisations of persons with disabilities in the European semester process and in the development of mainstream training organised or funded by the EU for its staff, relevant professionals at the EU and Member State level and relevant for persons with disabilities?

### **Article 9: Accessibility**

The <u>European Accessibility Act</u><sup>39</sup> was adopted on 17 April 2019. It must be transposed by Member States by 28 June 2022 and applied from 28 June 2025 in most part. The Act sets new EU-wide minimum accessibility requirements for a limited range of products and services.

The Act is a significant step in the journey of making the EU fully accessible for persons with disabilities, however, it falls short of being the horizontal act announced, as it essentially concerns the digital world. In particular, it fails to address accessibility of transport vehicles and infrastructure especially in urban transport. The built environment was included only as a voluntary clause for Member States, and other essential products and services such as household appliances were not covered at all. This means persons with disabilities still face significant barriers to accessing the built environment, products and services on daily basis.

The Act allows derogations in terms of application deadlines for several provisions, allowing the single European emergency number '112' to remain inaccessible until 2027 and in certain cases self-service terminals until 2045.

The Act also foresees revision and development of harmonised **European standards** which will help providers and procurers of services and products to meet the legal requirements of the Act. Harmonised standards therefore will be essential to ensure that persons with disabilities benefit from accessible services and products and they should be fully involved in their development. However, DPOs and other consumer organisations<sup>42</sup> have raised concerns about the inclusiveness, accessibility, and transparency of the European Standardisation system.<sup>43</sup> This hinders equal participation of organisations of persons with

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<sup>&</sup>lt;sup>39</sup> Directive (EU) 2019/882 of the European Parliament and of the Council of 17 April 2019 on the accessibility requirements for products and services (Text with EEA relevance)

<sup>&</sup>lt;sup>40</sup> The Act covers specific products and services mainly in the digital domain such as: computer and operating systems, ATMs, ticketing and check-in machines, smartphones, TV equipment related to digital television services, telephony services and related equipment, access to audio-visual media services such as television broadcast and related consumer equipment, services related to air, bus, rail and waterborne passenger transport, banking services, e-books, e-commerce.

<sup>&</sup>lt;sup>41</sup> In certain cases, such as in relation to the built environment the EU undertakes soft measures, such as promotion of the development and application of a European standard on accessibility and usability of the built environment. Due to their voluntary nature and lack binding obligations in the Accessibility Act, such initiatives are however not sufficient to ensure a harmonised approach to accessibility for persons with disabilities to the built environment throughout the EU.

<sup>42</sup> Such as ANEC

<sup>&</sup>lt;sup>43</sup> See EDF Position on draft standardisation request of the European Commission.

disabilities in the development of standards that will affect their daily access to essential services and products. To address this, the EU would need to revise Regulation (EU) No 1025/2012 on standardisation which at the moment is not on the EU agenda.

The <u>Public Procurement Directive</u> does include provisions requiring accessibility to be taken into consideration in drafting technical specification, as well as to be considered as an award and selection criteria. However, these provisions are not systematically used by public procurers and citizens do not have any remedial mechanism to challenge the purchasing decisions of public authorities when these are not accessible to them.

At the time of drafting of this report, the EU is also developing important legislation to regulate digital platforms and services such as internet access providers, cloud services, online marketplaces, app stores, and social media (<u>Digital Services Act</u> and <u>Digital Markets Act</u>), and Artificial Intelligence (<u>Al Regulation</u>). Despite active involvement in the public consultation process by the EDF network, the proposals of the European Commission for the mentioned Regulations fail to ensure accessibility of digital technologies (including Al) for persons with disabilities. They also make no reference to the CRPD.<sup>44</sup> In the meantime, the EU is setting general objectives for digitalisation for this decade (<u>Digital Decade – targets for 2030</u>) which do not sufficiently address accessibility for persons with disabilities, for example only accessibility of public online services are mentioned, leaving out private services. Accessibility is also not mentioned in relation to digital skill-building and development of ICT expertise in the EU. This may particularly impact people with disabilities who are not trained on digital technology, including women and older persons with disabilities.

It is important to note that both building environment and transport vehicles and related infrastructure serve as a bridge (or otherwise interfere as a barrier) between persons with disabilities and accessible products, goods, or services. More information about mobility is available **under Article 18**.

### Suggested questions:

- Given that the European Accessibility Act does not sufficiently address accessibility of
  the built environment, transport infrastructure, vehicles, vessels, aircrafts, including
  urban transport, and household appliances, what legal measures does the EU
  foresee to ensure right of persons with disabilities to access these in the European
  Union?
- When is the EU planning to revise Regulation (EU) No 1025/2012 on standardisation to ensure that organisations of persons with disabilities can participate in European Standardisation on equal footing with other (namely industry) actors, particularly ensuring balance of civil society and industry representation, equal voting rights, financial and accessibility measures to ensure this participation?

<sup>44</sup> See EDF Position Papers on EC proposals for the <u>Digital Services Act (DSA) and Digital Markets Act (DMA)</u>, as well as <u>Artificial Intelligence</u>.

- How is the EU going to ensure that persons with disabilities enjoy the same benefits
  from digitalisation and legal protection of their right of equal access to digital
  technologies, including digital platforms and services, AI, and other emerging
  technologies, as well as digital skill building, and other EU digitalisation objectives for
  the coming decade?
- How will the EU ensure that public procurers take into account accessibility for persons with disabilities when drafting the technical specifications of the tenders? Does the Commission consider introducing measures to ensure a remedial mechanism for users to challenge inaccessible products, services and infrastructure procured by the public sector?

### Article 10: Right to life

Persons with disabilities, in particular women, and persons with intellectual, psychosocial disabilities and autism, are at high risk of human rights abuse, including violations of the right to life. When placed, against their will in institutions, they may be subject to forced treatment, violence, unhygienic conditions, use of physical constraints, lack of food, water, and appropriate health care, all of which put their life in danger. For example, in January 2020, 8 persons with disabilities died during a fire in a residential institution in Czechia and in December 2021, 4 people with disabilities in a fire in a residential institution in Slovakia. Segregating persons with disabilities in residential institutions leaves them isolated and exposed to all kinds of risks, including death. 45

Such segregation and isolation, in combination with ineffective disaster risk reduction and emergency preparedness plans,<sup>46</sup> also expose persons with disabilities to increased risk of death during natural disasters. In July 2021,<u>12 persons with disabilities living in an institution in Germany lost their lives because they were not evacuated on time during flooding after heavy rainfall.</u>

In times of humanitarian emergencies, such as the pandemic of COVID-19, in some countries healthcare professionals were not able to provide the same level of care to everyone due to lack of equipment and underfunding of the healthcare sector. COVID-19 testing, outpatients and inpatients services were often inaccessible and ICU triage protocols in many European countries (directly or indirectly) resulted in discriminatory exclusions of persons with disabilities from lifesaving treatments.<sup>47</sup> This resulted in people in institutional settings facing the highest rates of infection and mortality from COVID-19. In Slovenia, for instance, 81% of the COVID-19 deaths were among care home residents.<sup>48</sup> That situation also particularly affected older persons, with a significant number of older persons with disabilities, such as with dementia, being impacted by the COVID-19 pandemic.<sup>49</sup>

<sup>&</sup>lt;sup>45</sup> See also the murder of 4 people with disabilities in an institution in Germany in 2021.

<sup>&</sup>lt;sup>46</sup> More information under article 11.

<sup>&</sup>lt;sup>47</sup> Autism-Europe, <u>Impact of COVID-19 on autistic people and their families across Europe</u> (December 2020)

<sup>&</sup>lt;sup>48</sup> A. Comas-Herrera, <u>Mortality associated with COVID-19 outbreaks in care homes: early international evidence</u> (May 2020)

<sup>&</sup>lt;sup>49</sup> Alzheimer Europe, Wellbeing of people with dementia and carers during the COVID-19 pandemic (2020)

### Suggested questions:

- What steps will the EU take to research and collect information into deaths in
  institutions, in particular EU-funded institutions, and promote the opening of
  investigations with effective sanctions for perpetrators (both state and non-state) and
  elimination and abolition of practices and treatment which put at risk people's lives?
- What initiatives will the EU take to ensure that during times of humanitarian
  emergencies and natural disasters disability inclusive responses are taken, including
  through sufficient research and data collection, and to ensure that and ethical medical
  guidelines for health care professionals adopted that do not discriminate against
  persons with disabilities and ensure their right to life on an equal basis with others?

### **Article 11: Situations of risk and humanitarian emergencies**

### **Work of DG ECHO**

The EU and 14 of its Member States have endorsed the 2016 Charter on Inclusion of Persons with Disabilities in Humanitarian Action. In December 2017, Commissioner Stylianides announced that the Directorate-General for European Civil Protection and Humanitarian Aid Operations (DG ECHO) will develop standards for addressing the needs of persons with disabilities in all EU-funded projects. DG ECHO published a Guidance Note on the Inclusion of Persons with Disabilities in EU-funded Humanitarian Aid Operations (June 2019). This could be regarded as a response to the recommendations made by the CRPD Committee in 2015. However, it is unclear how this has been achieved. For example, the new EU Disability Rights Strategy has no mention of how this Guidance Note will be implemented, and has no mention at all of how the EU plans to align its practical humanitarian guidance to the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action (2019).

In December 2017 Commissioner Stylianides also promised to consult persons with disabilities and their representative organisations in designing and carrying out these initiatives, in line with the principle of "Nothing about us without us". The latest version of DG ECHO partners' reporting guidelines (the 'Single Form', updated in May 2021) advises prioritising involvement of persons with disabilities (among other 'diverse groups') in project implementation. It also 'encourages' the use of the Washington Group Short Set of questions in data disaggregation and mentions mainstreaming of disability at various steps of the programme cycle. However, there is no reporting indicator that would measure degree of success of any of these initiatives, and although there is a Gender-Age Marker (to track gender and age sensitive actions and allow DG ECHO to monitor its own performance on integrating gender and age), there is no such marker for disability. There is also no routine training of partners on disability inclusion, either as disability-specific modules or with the topic integrated in ongoing mainstream training.

### **Disaster Risk Reduction (DRR)**

The EU developed an <u>action plan on Sendai implementation</u> in 2016. This action plan does include persons with disabilities among 'stakeholders to work with', but there is no further adherence to the disability-inclusive aspects of the <u>Sendai framework</u> or the <u>European</u>

Forum for DRR roadmap 2021-2030. Specifically, there is no mention of accessibility of early warning systems and risk information, empowerment and leadership of persons with disabilities (especially of women with disabilities), universal design in critical infrastructure, and the disaggregation of data by disability. Since 2016, EDF has been unable to obtain any news of improvements to this action plan in the field of disability inclusion or implementation that is inclusive of persons with disabilities, either as end users or with the participation of their representative organisations.

### **Climate action**

Although the EU Disability Rights Strategy (section 5.6) recognises the impact of climate change on persons with disabilities and the need to ensure that the green transition is fully inclusive, there is no explicit mention of this as part of EU external action in the European Disability Strategy Section 6. Similarly, the new <u>EU Strategy on Adapting to Climate Change</u> (2021) makes no reference to participation of persons with disabilities, through their representative organisations, in its implementation.

Overall, the "Green revolution" has almost completely bypassed person with disabilities, including women and girls with disabilities and young persons with disabilities. Many of them want to get involved but have no means of action, and even more of them are unaware and have little or no information regarding these subjects.

### **Migration**

The EU has not mainstreamed disability in its migration and refugee policies, the <u>Common European Asylum System</u>. In September 2020, it adopted a New Pact on Migration and Asylum which does not adequately include migrants, refugees, and asylum seekers with disabilities. The EU did also not issue guidelines to its agencies and member States that restrictive detention of persons with disabilities in the context of migration and asylum seeking is not in line with the CRPD, as recommended by the CRPD Committee.

### **Crisis communication**

The emergency number 112 is still not fully accessible across the EU. Recent infringement cases have for example been launched against Croatia, Czechia, Germany, Greece, and Spain related to equal access to the single European emergency number '112' to end users with disabilities.<sup>50</sup>

Further in relation to ensuring access for persons with disabilities to the single European emergency number '112', the EU has adopted the revised <a href="European Electronic">European Electronic</a>
<a href="Communications Code">Communications Code</a>. However, the Code only sets general obligation for ensuring accessibility of emergency communications to EU governments and refers to the European Accessibility Act to achieve this in practice. Designated call centres for handling and answering emergency communications will only be able to ensure accessible communications for persons with disabilities, including Deaf, hard of hearing, deafblind persons, and persons with speech disabilities, once they comply with the accessibility

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<sup>&</sup>lt;sup>50</sup> Infringement procedures can be launched in any policy area where the EU has competences to legislate. It can be started by the EU's own investigation or by a complaint from the public. So, anyone, including EDF members or individual citizens, can report a breach of EU law to the Secretariat-General and they will have to investigate whether an infringement procedure needs to be opened.

requirements set in the European Accessibility Act. Given that the Act allows EU governments to delay the application of provisions related to 112 until 2027, EU will largely fail to meet its obligation to ensure protection of persons with disabilities in emergency situations until then.

The <u>European Audiovisual Media Services Directive</u><sup>51</sup> also sets obligations to ensure accessible emergency information, including public communications and announcements in natural disaster situations, which is made available to the public through audiovisual media services. It does not specify however how this should be ensured, what should be minimum accessibility requirements be, nor foresees timelines to put measures in place.

### Suggested questions:

- What measures is the EU taking to ensure that all aspects of humanitarian action, disaster risk-reduction, climate action and migration policies and programmes are inclusive of and accessible to all persons with disabilities?
- What procedures are in place to ensure that all EU-funded projects under DG ECHO meaningfully involve and reach persons with disabilities, train staff and partners and report on inclusive implementation?
- How will the EU ensure that persons with disabilities have full access to emergency communications in the EU urgently, given that public centres handling emergency calls do not have to comply with Union-wide accessibility requirements until the year 2027?

### **Article 12: Equal recognition before the law**

Full legal capacity is still restricted across the European Union. Persons with disabilities, whose legal capacity has been denied or limited, are unable to enjoy and exercise an array of rights that come from EU law, such as the right to decide where to live, to get married, to sign employment or commercial contracts, to make financial transactions, to get a fair trial or to vote and stand as candidates in European and national elections.<sup>52</sup>

Since 2010, the Fundamental Rights Agency of the EU (FRA) has conducted several research on legal capacity and its impact on the right to decide of Europeans with disabilities, focusing specifically on citizens with intellectual and/or psychosocial disabilities, and on the right to vote in EU elections. There is no reliable and comparable data on the number of persons with disabilities deprived of legal capacity in the EU.<sup>53</sup> In its 2017 Mapping and Understanding Exclusion Report, Mental Health Europe (MHE) found out that "the majority of EU countries still practiced full deprivation of legal capacity and had plenary guardianship regimes, although a number of states were introducing more progressive legal capacity legislation." More worrying, MHE compared progress made between 2012 and 2017: "in the previous Mapping Exclusion report in 2012, several countries were planning or implementing progressive – and promising – legal capacity reforms. However, by 2017 our report found

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<sup>&</sup>lt;sup>51</sup> See more information about the Directive under article 21.

<sup>&</sup>lt;sup>52</sup> More information on the restriction linked to legal capacity to the right to vote and to stand for elections is available under article 29.

<sup>&</sup>lt;sup>53</sup> EU Fundamental Rights Agency, <u>Who will (not) get to vote in the 2019 European Parliament elections? Developments in the right to vote of people deprived of legal capacity in EU Member States, 2019.</u>

that only some countries have changed their relevant laws and practical implementation of supported decision-making remains wanting almost everywhere."<sup>54</sup> Also highlighted by FRA in its overview of legal reforms in EU Member States, Article 12 is "one of the largest number of reforms at the national level linked to CRPD ratification."<sup>55</sup>

Despite the now well evidenced breaches of the right to make decision of persons with disabilities, the EU has not taken measures to foster research, data collection and exchange of good practices on supported decision-making, in consultation with representative organisations of persons with disabilities, as requested by the CRPD Committee in its 2015 Concluding observations to the EU.

In addition, the European Commission indicated in its Disability Rights Strategy that it "will work with Member States to implement the **2000 Hague Convention on the international protection of vulnerable adults**<sup>56</sup> in line with the CRPD, including by way of a study on the protection of vulnerable adults in cross-border situations, notably those with intellectual disabilities, to pave the way for its ratification by all Member States." The <u>disability movement</u> is concerned that the implementation of this Convention could promote measures of substituted decision making if it is not adequately implemented in line with the CRPD.<sup>57</sup>

### Suggested questions:

- What steps will the EU take to provide robust data and comprehensive research about the impact of restrictions of legal capacity on the lives of persons with disabilities, especially for persons with intellectual and psychosocial disabilities (for example through research conducted by the Fundamental Rights Agency of the EU)?
- Which urgent actions will the EU take to eliminate restriction of legal capacity that hinder the rights of EU citizens with disabilities granted by the EU treaties, and ensure that the ratification and implementation of the 2000 Hague Convention on international protection of vulnerable adults promoted by the European Commission is done in compliance with the CRPD?
- What initiatives will the EU take to support the abolishment of substituted decisionmaking and replacement with supported decision-making across the EU, including through the promotion of data collection, research, and exchange of good practices?

<sup>54</sup> Mental Health Europe (MHE), <u>Mapping and Understanding Exclusion Report: Institutional, Coercive and Community-Based Services and Practices Across Europe</u>, 2017

<sup>&</sup>lt;sup>55</sup> EU Fundamental Rights Agency, <u>Implementing the United Nations Convention on the Rights of Persons with Disabilities (CRPD) - An overview of legal reforms in EU Member States</u>, 2015.

<sup>&</sup>lt;sup>56</sup> The Convention aims to facilitate decisions in cross-border situations in relation to persons who "by reason of an impairment or insufficiency of their personal faculties, are not in a position to protect their interests". In particular, the convention: (1) determines which courts have jurisdiction to take protection measures, (2) determines which law is to be applied and who may be a "vulnerable person" and (3) establishes a system of central authorities which should cooperate, locate "vulnerable adults", and give information on the status of vulnerable persons to other authorities.

<sup>&</sup>lt;sup>57</sup> The European Commission has published a consultation on <u>Civil judicial cooperation – EU-wide protection for vulnerable adults</u> that includes consideration on the 2000 Hague Convention. The consultation is open until 29 March 2022 and EDF will contribute to it.

# Article 13: Access to justice Criminal matters

The EU guarantees the rights of victims of crimes and people suspected or accused under several directives.<sup>58</sup> This framework specifically considers the rights of victims with disabilities in access to justice, and more in particular accessibility of premises, communication and information.<sup>59</sup> However, the existing directives are often not fully transposed and implemented by member states.

Despite the existing legislation, many victims with disabilities and people with disabilities suspected or accused of crimes (including children), are not granted their rights. Even when measures are available, they are often not accessible to victims, suspects and accused with disabilities due to inaccessibility or the lack of provision of accommodation. Often women and girls with disabilities are not believed when they report violence, especially women with intellectual or psychosocial disabilities. Persons on the autism spectrum, and with intellectual or psychosocial disabilities, and more particularly, victims who have had their legal capacity removed, are often denied participation in criminal proceedings.

In addition, inaccessible victim support services are a significant barrier for many victims with disabilities, in particular women with disabilities and persons with intellectual and psychosocial disabilities or autism who most often do not benefit from these services. Mechanisms for reporting abuse and bullying do not take into consideration the needs of women and children with disabilities since their testimonies are either discredited or they require the ability to use certain forms of communication and to have access to them.<sup>60</sup>

The rights of victims with disabilities and children with disabilities in the criminal justice system are included in the <u>Strategy on victims' rights 2020-2025</u> and the <u>EU Strategy on the rights of the child</u> adopted in 2020 and 2021. However, further actions are urgently needed to monitor the transposition and implementation of the frameworks by EU Member States and better inform organisations of persons with disabilities and victims support organisations of the rights and needs of persons with disabilities in the justice system.

proceedings; Directive 2010/64/EU of the European Parliament and of the Council of 20 October 2010 on the right to interpretation and translation in criminal proceedings.

<sup>&</sup>lt;sup>58</sup> Of particular relevant for persons with disabilities are: Directive 2012/29/EU of the European Parliament and of the Council of 25 October 2012 establishing minimum standards on the rights, support and protection of victims of crime (Victims' Rights Directive); Directive 2012/13/EU of the European Parliament and of the Council of 22 May 2012 on the right to information in criminal

<sup>&</sup>lt;sup>59</sup> For instance, the <u>Victims' Rights Directive</u> specifies that "Member States should ensure that victims with disabilities are able to benefit fully from the rights set out in the Directive, on an equal basis with others, including by facilitating the accessibility to premises where criminal proceedings are conducted and access to information." The <u>Directive on procedural safeguards for children who are suspects or accused persons in criminal proceedings</u> makes specific references to children with disabilities, including children with intellectual disabilities, accessible language and the right to education of all children deprived of their liberty.

<sup>&</sup>lt;sup>60</sup> EDF Manifesto on the rights of women and girls with disabilities (2011).

### Civil and commercial matters

In 2003, the EU adopted a directive to establish common rules on **legal aid available in cross-border disputes**<sup>61</sup> applicable to civil and commercial proceedings. While the costs covered by the legal aid include interpretation, translation of documents and travel costs, it is not clear whether it also covers the specific needs of persons with disabilities facing cross-border disputes, including sign language interpretation, translation of documents in easy-to-read or braille, and travel costs of a personal assistant.

### **Digitalisation of justice**

In 2020, the European Commission launched a package on digitalisation of justice in the EU, including regarding cross-border judicial cooperation. The <u>Communication on Digitalisation of justice in the EU</u> announced that further proposal could "ensure that any electronic access points established for use by the general public cater for persons with disabilities" and that IT tools should be accessible to users with disabilities. It is not clear how the European Commission plans to address other barriers faced by persons with disabilities such as lower access to the internet and digital tools, affordability of relevant digital services and products, and lower digital skills. Et is also not clear how the impact on persons with disabilities will be assessed and monitored.

### **EU Justice Scoreboard**

Launched in 2013, the <u>EU Justice Scoreboard</u> is a tool used by the European Commission to monitor justice reforms in Member States. Unfortunately, in its current form it provided very limited information on effective access by persons with disabilities.<sup>63</sup> Such information is necessary to support reforms in national justice systems required to make justice systems more effective. EDF recommended that the European Commission to establish a "CRPD compliant-justice" indicator similar to the "child-friendly justice" indicator.<sup>64</sup>

### Suggested questions:

How will the EU monitor the adequate implementation of its directives on access to
justice and sanction member states that do not ensure the rights of person with
disabilities? How will it ensure that it contributes to full access for all persons with
disabilities to the justice system, including victim's support services in light of the

<sup>61</sup> Council Directive 2002/8/EC of 27 January 2003 to improve access to justice in cross-border disputes by establishing minimum common rules relating to legal aid for such disputes

<sup>&</sup>lt;sup>62</sup> The <u>Europe's Digital Decade</u>: digital targets for 2030 for example aims to support digital skill-building of EU citizens, but does not foresee ensuring this is accessible for persons with disabilities. A study indicates that in 2012, on average 7 out of 10 European citizens had Internet access at home but only 5 out of 10 among those who declared an activity limitation connected to impairment or disability. See Scholz, Yalcin and Priestley, <u>Internet access for disabled people</u>: <u>Understanding sociorelational factors in Europe</u> (2017). According to the <u>EU Strategy for the Rights of Persons with Disabilities only 64,3% of persons with disabilities aged 16+ have an internet connection at home compared to 87.9% of persons without disabilities (p.6).</u>

<sup>&</sup>lt;sup>63</sup> The information available on persons with disabilities in the 2020 and <u>2021 Justice Scoreboard</u> only focused on Deaf, hard of hearing, partly sighted and blind people. It included "online information for visually or hearing impaired," training in communication for judges on "communication with visually/hearing impaired," and survey conducted among court users or legal professional on "needs and satisfaction of visually/hearing impaired."

<sup>&</sup>lt;sup>64</sup> EDF recommendations on the 2022 EU Justice Scoreboard

Victims' Rights Strategy? How will the initiatives on digitalisation of justice advance the rights of persons with disabilities?

- How does the EU ensure that its 2003 directive establishing common rule on legal aids in cross-border disputes is implemented in a way to cover the rights and specific needs of persons with disabilities facing cross-border disputes?
- What are the plans of the EU to collect data on access to justice by persons with disabilities, including using the EU Justice Scoreboard? How will the EU use this tool to collect information about CRPD compliant justice systems?

### **Article 14: Liberty and security of the person**

### Involuntary treatment and placement

Many persons with disabilities living in the EU continue to be involuntary detained and treated in psychiatric hospitals, and other institutions, based on actual or perceived disability.<sup>65</sup>

The EU is considered as "the <u>Council of Europe</u><sup>66</sup>'s most important institutional partner at both political and technical levels" and the relationship between the two organisations are based under a <u>Memorandum of Understanding</u>. All EU Member States are members of the Council of Europe. However, the EU <u>fails to take position against a Council of Europe's draft additional protocol concerning the "protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment".<sup>67</sup></u>

### Pre-trial detention and convicted persons

Detainees with disabilities continue to face many violations of their rights in EU Member States. Such violations are described in a report of the Council of Europe on <u>Detainees with disabilities in Europe</u> published in 2018. They range from the non-recognition of their disability, to lack of access to treatment, failure to provide assistance and support and even ill-treatment and torture. There is also a disproportionate number of persons on the autism spectrum and persons with intellectual and psychosocial disabilities in prison.<sup>68</sup>

<sup>&</sup>lt;sup>65</sup> For example, the European Deafblind Union reports that Deafblind people are sometimes still detained in psychiatric institutions because of communication barriers.

<sup>&</sup>lt;sup>66</sup> The Council of Europe is an international organisation founded in 1949 with the aim to uphold human rights, democracy, and the rule of law in Europe. It has <u>47 member states</u> which have ratified the European Convention of Human Rights and are therefore overseen by the European Court of Human Rights, an entity separate from the European Union. 46 member states have ratified the CRPD.

<sup>&</sup>lt;sup>67</sup> EDF raised several times the issue of the draft additional protocol to the Oviedo Convention in letters sent to the EU Commissioner on Equality and the Commission for Health, as well as the Council of the EU's Working Party on Human Rights (COHOM) and Working Party on the OSCE and Council of Europe. EDF also met with the Delegation of the EU to the Council of Europe. On 25<sup>th</sup> of October 2021, 10 members of the European Parliament sent a letter to the Committee of Bioethics of the Council of Europe on the topic.

<sup>&</sup>lt;sup>68</sup> For example, in France, "nearly a quarter of detainees are said to have psychotic disorders". See Parliamentary Assembly of the Council of Europe, <u>Detainees with disabilities in Europe</u> (2018), 3.3.

So far, there are no EU rules on detention. The European Commission is in the process to develop a <u>recommendation on detention</u> but it is not certain to which extend it will pay attention to the rights of detainees with disabilities.

In 2017, the European Parliament adopted a <u>resolution on prison systems and conditions</u>. The resolution recognised the failure of EU Member States to protect the rights of prisoners with disabilities. It called on the Commission to carry out a comparative study to analyse Member States' alternative measures and to launch a European Forum on prison conditions to support the dissemination of national best practices, as well as to monitor and collect information and statistics on detention conditions in all Member States and to publish detailed reports on the situation of prisons in Europe at five-year intervals, following on from the adoption of the resolution.

### **Detention based on migratory status**

Migrants and asylum-seekers, including those with disabilities continue to be detained throughout Europe. Often, they are detained in conditions which do not take into account the necessary support and reasonable accommodations that they need, as they are not identified as persons with disabilities upon their arrival to Europe. They face inaccessible services (including assistance programmes) and facilities, lack of access to medical care, assistive technologies, and other disability related services (such as sign language interpretation and mechanisms of supported decision making, etc.). <sup>69</sup> The migration decision-making procedure is not accessible for all persons with disabilities and information and communication is not provided in accessible formats.

### Suggested questions:

- What steps is the EU taking to oppose to the draft additional protocol to the Oviedo Convention and promote voluntary measures in EU Member States?
- What steps will the EU take to ensure that all funding and measures on prisons and detention centres, including its upcoming Recommendation on detention, are disability inclusive and aimed at providing support and reasonable accommodation to persons with disabilities?
- What initiatives will the EU take to ensure that all funding and measures regarding migration are disability inclusive and that persons with disabilities are not arbitrarily detained?

# Article 15: Freedom from torture or cruel, inhuman, or degrading treatment or punishment

The EU prohibits trade in certain goods which could be used for capital punishment, torture or other cruel, inhuman or degrading treatment or punishment.<sup>70</sup> In 2019, <u>guidelines</u> were

<sup>&</sup>lt;sup>69</sup> EDF took part in October 2016 in a <u>mission of the European Economic and Social Committee</u> (EESC) to Greece to investigate the situation of refugees and asylum seekers with disabilities; Human Rights Watch Report 'Greece: Refugees with Disabilities Overlooked, Underserved - Identify People with Disabilities; Ensure Access to Services'

<sup>&</sup>lt;sup>70</sup> Regulation (EU) 2019/125 of 16 January 2019 concerning trade in certain goods, which could be used for capital punishment, torture or other cruel, inhuman, or degrading treatment or punishment. It is legally binding and directly applicable in all EU Member States.

adopted by the Council of the EU to provide more details on EU's actions with third countries on torture and other cruel, inhuman or degrading treatment and punishment. The guidelines call for special protection and attention to the vulnerable situation of persons with disabilities, amongst other groups in all EU's actions towards third countries in prevention of torture and other ill-treatment. No details are given however about what the specific needs and rights are of persons with disabilities, especially those living in closed settings. Similar guidelines to prevent torture and ill-treatment inside the EU does not exist.

### Suggested question:

 What steps will the EU take to ensure that the rights and needs of all persons with disabilities are included in EU's actions to prevent torture and other forms of illtreatment inside and outside the EU?

### **Article 16: Freedom from violence**

Persons with disabilities living in the EU continue to be victims of violence and abuses, especially children and women with disabilities,<sup>71</sup> persons with intellectual disabilities and autism, older persons with disabilities and persons with disabilities living in closed settings, such as institutions and psychiatric facilities.

### For example:

- 50% of persons with disabilities reported having experience of harassment, comparing to 37% of persons without disabilities (over a 5-year period)<sup>72</sup>
- 17% of persons with disabilities have experienced physical violence, comparing to 8% of persons without disabilities<sup>73</sup>
- Women with disabilities are two to five times more likely to face violence than other women, and 34 % of women with a health problem or a disability have experienced physical or sexual violence by a partner in their lifetime<sup>74</sup>

The European Commission adopted a series of policies to combat violence, trafficking, harmful practices and protect the integrity of the persons and the rights of victims (namely the <u>Strategy on Victims' Rights</u>, 75 the <u>Strategy toward the eradication of trafficking in human beings 2021-2025</u>, the <u>Strategy on a more effective fight against child sexual abuse</u>). While the Strategy on Victims' Rights covers the rights of persons with disabilities, adults and children with disabilities remain mostly invisible in the two other strategies.

In relation to women and girls with disabilities, the <u>Gender Equality Strategy</u> declared that the EU will take action to combat forced sterilisation and abortion, but so far, it has not taken measures in this regard. In addition, the <u>European Institute for Gender Equality</u> does not collect <u>statistics on violence against women</u> disaggregated by disability and does not

<sup>&</sup>lt;sup>71</sup> See EDF Position paper on violence against women and girls with disabilities in the EU (2021).

<sup>&</sup>lt;sup>72</sup> FRA, Fundamental Rights Survey: CRIME, SAFETY AND VICTIMS' RIGHTS (2021), page 22.

<sup>&</sup>lt;sup>73</sup> Ibid, page 18.

<sup>&</sup>lt;sup>74</sup> European Parliament resolution on the situation of women with disabilities (2018/2685(RSP)).

<sup>&</sup>lt;sup>75</sup> More information under Article 13 on access to justice.

adequately include the disability perspective <u>in its work and studies on gender based</u> violence.

The European Commission announced that it will make a proposal for a Directive on combating violence against women and a Recommendation on the prevention of harmful practices; but it is not certain to which extend they will be disability inclusive.<sup>76</sup>

There is a lack of data concerning violence against children with disabilities (as highlighted in a <u>FRA report</u> from 2015)<sup>77</sup> and specific measures to protect them from violence.

### Suggested questions:

- What measures will the European Commission propose to ensure it includes persons with disabilities, in particular women and children with disabilities, in the implementation of its strategies on victims' rights, eradicating trafficking and fighting child sexual abuses, and in the design of the Directive on combating violence against women and Recommendation on the prevention of harmful practices?
- What steps will the EU take to research and collect information on violence against
  persons with disabilities, including against children as well as women with disabilities
  through the European Institute for Gender Equality, and those living in closed settings
  such as institutions, psychiatric hospitals, and detention centres?

### **Article 17: Integrity of the person**

The EU has shared competence on common safety concerns in public health matters and supporting competence in health protection. The EU has competence to carry out research and technological activities to define and implement programmes.

### Research

The ethics self-assessment and ethics review for research funded by the EU under the Horizon Europe research and innovation programme, Digital Europe and the European Defence Fund do not ensure that persons with disabilities involved are enabled to give their informed consent and does not provide consent forms in accessible and Easy to Read formats. The Guidance on how to complete the ethics self-assessment directly refers to "persons unable to give informed consent." While it requires candidates to indicate "informed consent procedures," it also makes exceptions for informed consent if national laws provide

<sup>&</sup>lt;sup>76</sup> As mentioned under Article 6, the EU and 6 of its member states have still not ratified the Council of Europe's Convention on preventing and combatting violence against women and domestic violence (Istanbul Convention). Ratification of the Convention would require member states to criminalise forced abortion and sterilisation. Currently, not all members of the EU criminalise those abuses.
<sup>77</sup> FRA report from page 50 -51: "The EU has acknowledged that official and comparable data on children with disabilities' enjoyment of their rights in EU Member States is lacking. (....) Despite the CRPD's obligations, a significant gap in knowledge about the prevalence and extent of violence against children with disabilities remains. Some countries have established mechanisms for collecting data on violence against children in general, but do not collect information on whether or not the children have disabilities."

for an exception, for instance for public interest. It also explicitly allows for substituted decision-making procedures.78 79

### Involuntary treatment and placement

As explained under Article 14, persons with autism, intellectual and psychosocial disabilities living in the EU continue to experience involuntary treatment and placement. Research has shown that these experiences are 'overwhelmingly negative' and cause trauma and fear. The European Commission has not engaged with organisations of persons with disabilities and did not take any actions to decrease the use of coercive practices in psychiatry in the EU.

### Forced sterilisation, abortion, and genital mutilation

In addition, as referred under **Article 16**, many women with disabilities are still denied the right to reproductive freedom under the pretext of their wellbeing. Forced sterilisation, genital mutilation and coerced abortion are just some clear examples of denial of rights that many women, adolescents, and children with disabilities suffer (including intersex children and adolescents), without giving their consent or fully understanding the intentions. Those abuses particularly affect members of ethnic minorities such as Roma women<sup>80</sup> and women under guardianships and/or living in institutions.81

- What steps will the European Commission take to ensure that research funded by the EU does not allow substituted decision making and to explicitly prohibit this practice in its ethics guidelines?
- What measures has the EU taken to adopt public health policy measures to ensure the protection of the integrity of all persons with disabilities and, in particular, their right to informed consent to medical treatment?
- What measures has the EU to promote and undertake research to publicise the reality of sterilisation in persons with disabilities in Member States, taking into account gender, age and type of disability and providing accurate statistics on forced sterilisation?

<sup>&</sup>lt;sup>78</sup> See page 9 of the guidelines: "For children (or other persons unable to give informed consent, e.g., certain elderly populations, persons judged as lacking mental capacity), the consent must be obtained from the parents/legally authorised representative and it must be ensured that they have sufficient information to enable them to provide this on behalf and in the best interests of the children." For medical activities or other activities involving humans requiring informed consent, the guidelines require to follow the procedures for informed consent that are described in the Declaration of Helsinki and the Oviedo Bioethics Convention. The two Conventions do not comply with the CRPD as their provision on informed consent are based on substituted decision making.

<sup>&</sup>lt;sup>79</sup> The problem also lies in the fact that some persons with disabilities, without the adequate support, are unable to give informed consent. For example, due to the lack of government funded interpreting hours, some of the Deafblind, Deaf, or hard of hearing persons have substituted interpreting (e.g., family members, friends,) which can be problematic since some of them are probably not competent to interpret the official situations and/or some of them may even work in their own interest, and not represent the interest of the disabled person.

<sup>80</sup> European Parliament resolution 2018/2685(RSP)

<sup>81</sup> The CRPD Committee raised concerns over the fact that several EU Member States still authorise forced sterilisation and abortion in their legislation, including in Croatia, Czechia, Germany, Lithuania, Slovakia, and Spain.

### **Article 18: Freedom of movement**

The EU provides citizens with freedom to move in countries other than their own to work and study (Article 3(2) of the <u>Treaty on European Union</u> (TEU) and Articles 4(2)(a), 20, 26 and 45-48 of the <u>Treaty on the Functioning of the European Union</u> (TFEU).

Today, 17 million EU citizens live and work abroad in another EU country. <sup>82</sup> This mobility, however, is extremely limited for persons with disabilities. Fragmentation of disability assessment systems has led to a fractured understanding of what disability is, how different "levels" of disability are measured, and who qualifies for social protection and social assistance allowances. The inconsistent types of assessment, qualifications for allowances and administrative processes inherently deprive persons with disabilities of their rights enshrined in the EU treaties to freedom of movement. It makes getting support in another EU Member State extremely difficult, if not impossible, and at the very least will require the person to undergo a lengthy and strenuous process to get the support they require. Although the type of services and support on offer vary between Member States, not least because the barriers in the different countries and localities cannot be easily compared, a mutual recognition of disability assessment between the EU Member States would allow persons with disabilities to access support available in their new country of residence, on the same level as other persons with similar requirements where they live.

The lack of recognition of disability assessment between EU Member States can, for example, impact students who would like to study abroad with EU funded programme ERASMUS+ but cannot take their personal assistance with them. Mutual recognition of the disability status would be a step forward, and this could be facilitated by a "European Disability Card", as foreseen in the European Disability Rights Strategy 2021-2030<sup>83</sup> (flagship initiative, mentioned on page 9). However, at the time of drafting this report we do not know if the Disability Card would achieve this important objective.

The <u>European Parking Card for persons with disabilities</u> ("Blue Badge") has been a long-standing and useful tool for better mobility of persons with disabilities. However, the original Recommendation is outdated and fails to harmonise important aspects such as the conditions under which a person can receive the Card, the parking-related advantages that are attached to the Card, or the format and anti-fraud measures of the Card. Therefore, a new proposal ideally for binding legislation to further harmonize the Card throughout the EU would be necessary.

Persons with disabilities cannot transfer their disability allowance from their Member State of origin when they move to a different Member State temporarily. In practice, this denies persons with disabilities who hold the citizenship of one of the 27 EU Member States, as well as Norway, Iceland, Liechtenstein, and Switzerland, of the right they hold under the EU treaties to live and work freely throughout the EU. Even when they move to a different Member State permanently, they often have difficulties in getting their disability status recognised and face additional bureaucratic burdens. This situation is also true for families of persons with disabilities who are also facing barriers concerning the support they and their relatives receive.

<sup>82</sup> Available at: https://europa.eu/euandme/passion/work-and-live-abroad\_en

<sup>83</sup> Flagship initiative, mentioned on page 9 of the Strategy.

### Suggested question:

- How will the EU address the difficulties faced by persons with disabilities concerning the "portability" of their (disability) allowances when moving abroad?
- How will the EU ensure a mutual recognition among EU countries of disability assessment?
- What are the plans of the EU concerning the harmonisation of the eligibility and mutual recognition of the Parking Card across EU countries?

### Article 19: Living independently and being included in the community

Over 1 million persons with disabilities in the EU still live in institutional settings. All In many cases, they even live far away from their family and place of origin. While it is theoretically forbidden for EU funds to be invested in institutional care settings, there have been numerous complaints of EU money being used to refurbish existing institutions or to replace them with other alternatives that reproduce institutional settings. We see such structures being supported with EU funds, denying persons with disabilities of their choice of how to live as underlined in General Comment 5. Alleged human rights abuses in a social care institution for persons with disabilities, which had received funding from the European Structural and Investment Funds, were the basis of a complaint to, and eventual decision by the European Ombudsman in 2019.

To guide Member states' efforts of deinstitutionalisation and to strengthen the monitoring of the use of the European Structural & Investment Funds with the meaningful engagement of representative organisations of persons with disabilities, the EU developed a guide for Member States, as part of the last Multiannual Financial Framework, on involvement of partners such as NGOs in the governance process for the use of funds. Known as the <a href="European Code of Conduct on Partnership, it">European Code of Conduct on Partnership, it</a> is legally binding and requires Member States to be transparent in the selection of partners, provide sufficient information to partners and give them sufficient time to make their voice heard in the consultation process, ensure that partners are involved in all stages of the process, from planning to evaluation, support capacity-building of partners and create platforms for mutual learning and exchange of good practice. The Commission has been given permission to rework the Code of Conduct for the new funding period starting in 2021.

As of 2021 the EU has new Regulations to guide the use of EU funds that benefit persons with disabilities, such as the <u>European Social Fund Plus</u> (which invests in social inclusion of marginalised groups) and the <u>Regional Development Funds</u> (which helps develop infrastructure and services) and the <u>Common Provisions Regulation</u> (which outlines rules for the use of the two funds mentioned above and a number of others). The guiding Regulations refer to the need for Member States to have a strategy for the implementation of the CRPD to make use of these funds, and to prioritise investment in the transition from institutional to community-based care and services. However, the implementation of the Regulation is still not a given, and we risk seeing continued misuse of funds, particularly when it comes to investment in institutions. Most commonly we see funds being used to refurbish existing institutions under the guise of investments for improving energy efficiency. In other cases, we

 $<sup>{}^{84}\</sup>underline{\ \ }\underline{\ \ \ }\underline{\ \$ 

see entirely new institutions being built using EU funds because of lack of understanding by National Managing Authorities of what institutions are, and what types of community-based services they should be investing in.

More worrying still is that the EU has created another funding mechanism in the wake of the COVID-19 crisis called the "Recovery and Resilience Facility". It is a €723.8 billion fund to boost recovery from the pandemic. The speed at which the Recovery and Resilience Facility was adopted and the Member States' plans for spending it were developed resulted in insufficient or non-existent consultation of disability organisations. Furthermore, this money does not need to adhere to the same strict rules as other EU funding, making the risk that it could be invested in institutional care for persons with disabilities even greater.

The European Commission has financially supported the activity of the <u>European Expert</u> <u>Group on the Transition from Institutional to Community-Based Care</u> which, as part of its operations, has created a <u>checklist</u> for the national authorities in each Member State on how to ensure EU funds do not go towards financing or maintaining institutional care. This is however not an official EU document and carries no legal obligation.

### Suggested questions:

- How will the European Code of Conduct on Partnership be improved in the coming funding period to ensure better involvement of persons with disabilities and their representative organisations?
- What is the EU planning to have guidance on the use of EU funds for persons with disabilities, in the form of an official EU guidance document?
- How does the EU plan to improve its monitoring on the use of EU funds, particularly
  the Recovery and Resilience Facility, and how will you make it easier for citizens and
  NGOs to scrutinise and raise the alarm for EU-funded actions that are not CRPD
  compliant before they go into development?

### **Article 20: Personal mobility**

Persons with disabilities still cannot travel freely in the EU, despite this being one of the four fundamental freedoms of the EU. Some specific challenges are the lack of harmonised platform height levels throughout the EU, which results in difficulties to access trains, the lack of appropriate compensation for damaged, lost, or destroyed mobility equipment when flying, the lack of binding rules on accessible urban transport including new e-mobility solutions, or the fact that persons with disabilities still have to give 24 hours' notice if they want to receive assistance at train stations.

The rights of passengers with disabilities are still not fully protected and the provision in Regulation 1177/2010 to allow travelling with an assistant for free has not been systematically included in the other Regulations on passengers' rights. There are a lot of differences between transport operators regarding the travelling conditions with a personal assistant and which types of disabilities are eligible for such assistance.<sup>85</sup> Furthermore, it has

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<sup>&</sup>lt;sup>85</sup> Discrepancy across the railway companies regarding the right to travel with a personal assistant: for example on <u>Thalys website</u> (trains between Belgium, France, Germany and the Netherlands), it is clearly mentioned that (only) wheelchair users can benefit from a reduced fee for their assistant, while

to be ensured that travelling with an assistant does not become an obligation for the passenger either.

There is still a fundamental lack of accessibility of all modes of transport, in spite of EU Regulation being in place in some areas. But there are also gaps in EU legislation, for example in urban transport. No EU-level legislation exists for the accessibility of metros, trams, buses, or trolley buses. <sup>86</sup> Lack of standardisation and harmonisation of accessibility standards leads to repeating the same mistakes over and over again, as each city or municipality starts more or less from scratch.

In the existing legislation on Passengers' Rights, the right to receive assistance at stations, airports, or bus terminals is still subject to a lot of conditions which do not allow persons with disabilities to exercise their right to mobility. For example, receiving assistance for rail travel is subject to 24-hour notification period which does not allow for spontaneous travel, in spite of a recent revision of Regulation 782/2021on Rail Passengers' Rights. Bus and coach passengers with disabilities must give 36 hours pre-notification and are able to get assistance only at designated stations of pre-determined long-distance routes.

Travelling with personal mobility equipment on public transport has not improved either. Frequently damaged, lost, or destroyed mobility equipment, such as wheelchairs, are still not being fully compensated for when travelling by air, even though Regulation 261/2004 regulates the airlines' liability for lost luggage. And many transport providers do not allow for mobility equipment such as e-scooters or even larger electric wheelchairs on buses or trains. This remains an obstacle to personal mobility of many persons with disabilities.

Even though Regulation 1107/2006 guarantees passengers with disabilities' right to transport, they also still allow denial of reservation and boarding due to 'safety considerations' and inaccessible carrier/vehicle and station/port design. Furthermore, while Regulation 261/2004 grants financial compensation for a delayed or cancelled flight or if passengers have been denied boarding against their will, Regulation 1107/2006 does not oblige airlines to financially compensate passengers that have been denied boarding because of their disability.

There are also remaining issues with the Rail Accessibility Regulation (Regulation 1300/2014 on Technical Specifications for the Interoperability of the Union's Rail System for Persons with Disabilities ("TSI-PRM")). It concerns accessibility of rolling stock and stations but it still allows in some cases for inaccessible trains to be manufactured and sold, not allowing for independent and spontaneous access. There are for example exemptions for double-deck trains and for restaurant cars, and the platform-train interface which causes many of the problems for independent boarding is not addressed in the Regulation.

Regulation 1315/2013 on the Trans-European Networks should take accessibility into account so that no new or renovated infrastructure that is paid for by EU money can remain

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with <u>SNCF</u> (train in France) it is based on the % of disability and does not discriminate according to the type of disability.

<sup>&</sup>lt;sup>86</sup> The regulations and rules are uneven among the Member states which makes it difficult for persons with disabilities to plan the travels and places to go to, impacting their freedom of movement within the EU.

inaccessible. The Regulation should also include provisions for consistent monitoring of this requirement.

Finally, boats and ferries under <u>Directive 2009/45 on safety rules and standards for passenger ships</u> also often lacks basic accessibility features such as accessible communication and boarding, as well as circulation on board of the vessel. <u>Regulation 1177/2010</u><sup>87</sup> does not include excursion or sightseeing boats and, similar to <u>Regulation 1107/2006</u><sup>88</sup> leaves a "loophole" to the right to travel if a person with disabilities cannot comply with "applicable safety requirements". In turn, the transport provider can oblige a person with disabilities to be accompanied – this should be free of charge, but still constitutes discriminatory treatment.

# Suggested questions:

- How will the EU ensure that passengers with disabilities enjoy same level of rights to
  access rail, waterborne, air, bus and coach transport, as other citizens by relevant EU
  Regulations, for example addressing issues in relation to denied boarding,
  compensation of lost or damaged mobility equipment, the same level of spontaneity
  and independence as passengers without disabilities?
- Personal mobility is often a question of accessibility as well how is the accessibility addressed in EU legislation to allow fully independent and spontaneous travel? How is the EU going to ensure that EU funding is not used to build inaccessible transport infrastructure and how does it plan to monitor that this is effectively enforced?
- How is the EU planning to harmonise requirements of level access to rail from station platforms across the EU as well as legislative gaps which allow procurement of inaccessible trains?

# Articles 21: Freedom of expression, opinion, and access to information

Despite some legislative progress in the past years, <sup>89</sup> in most of EU countries equal access to information and communication constitutes a barrier to the full participation of persons with disabilities in all aspects of life in the so-called information societies. The lack of accessibility, adapted formats and means of communication (including in national sign language), and the lack of suitable assistive and accessible technologies still hinders the freedom of expression and access to information of persons with disabilities.

The EU has made a step forward toward strengthening legal obligation of States to ensure accessibility of televised broadcasts and on-demand services through the <u>revised</u>

<u>Audiovisual Media Services Directive</u>, which was adopted in November 2018. Nevertheless, the Directive is quite vague and does not prescribe any timelines, or qualitative and quantitative targets to reach this goal. The ambiguity of the EU legal text will mean that persons with disabilities have different level of access to information provided to the general

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<sup>&</sup>lt;sup>87</sup> Regulation (EU) No 1177/2010 of the European Parliament and of the Council of 24 November 2010 concerning the rights of passengers when travelling by sea and inland waterway and amending Regulation (EC) No 2006/2004 Text with EEA relevance

Regulation (EC) No 1107/2006 of the European Parliament and of the Council of 5 July 2006
 concerning the rights of disabled persons and persons with reduced mobility when travelling by air
 Such the transposition and implementation of the Web Directive, the Accessibility Act, Marrakesh

Treaty, and the Audiovisual Media Services Directive and the Electronic Communications Code.

public by TV broadcasters (e.g., news or emergency warnings<sup>90</sup>). The Directive also does not ensure accessibility of video-sharing (e.g., YouTube, Dailymotion) and social media (e.g., Facebook, Twitter) platforms, even though it recognises the increasing public importance of these platforms as channels to share information, entertain, educate, and shape and influence public opinion. It also does not ensure that audiovisual sections of news websites are accessible for persons with disabilities. These creates barriers both to right of information and freedom of expression.

Access to information, communication, and knowledge in national sign languages within the EU is not guaranteed, even though all the EU Member States have now officially recognised their national sign languages. Even though national sign languages are fully fledged languages in their own right in all the EU Member States, the EU fails to consider them as part of the multilingualism of the EU and does not guarantee access to information, communication and knowledge through them.

Access to information, communication and freedom of expression is further hindered by the lack of uniform approach to availability, quality, and affordability of assistive technologies across the EU. In the absence of an EU legal framework, provision of assistive technologies to persons with disabilities remains under Member State regulations. Different certification schemes and provision models at national level create fragmentation in the Union market, difficulties to the assistive technology industry and, more importantly, fail to ensure equal level of access and choice to these technologies by persons with disabilities. This causes, for example, that the same product costs differently across EU countries, and that persons with disabilities cannot access a specific assistive technology sold in another EU country. Additionally, persons with disabilities must go through lengthy and complex administrative processes, sometimes very medical oriented, to access these technologies, and, in some cases, certain national delivery models discriminate against certain persons with disabilities, based on their age or work status. <sup>91</sup>

# Suggested questions:

- How is the EU ensuring the use of alternative formats for persons with disabilities, especially use of live subtitling/captioning, Sign language interpretation, Braille and Easy-to-read?
- How will the EU ensure that persons with disabilities enjoy equal access to videosharing and social media platforms which play increasing role in receiving and sharing information? How will the EU ensure that persons with disabilities have equal access to news websites, including to their audiovisual content?
- How does the EU plan to ensure that assistive technologies are made available to persons with disabilities in an equitable and affordable manner across the Union?

#### **Article 22: Respect for privacy**

In a world where the use of emerging technologies is drastically increasing, there are concerns that unregulated use of artificial intelligence and automated decision-making creates new risks of discrimination for persons with disabilities, but also a significant risk to

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<sup>&</sup>lt;sup>90</sup> See under article 11.

<sup>&</sup>lt;sup>91</sup> For more information see <u>EDF paper on assistive technologies in the EU</u>.

their right to privacy. 92 Many people are not well-informed about how using online services or connected devices is affecting their privacy. In the EU, citizens have greater rights in relation to the protection of their personal data, thanks to the implementation of the General Data Protection Regulation (GDPR) but few people have practical knowledge of these rights and how to exercise them.

Questions have been raised about **detection of assistive technologies**. For example, some accessibility experts raised concerns about screen reader or browser detection. Use of assistive technology or digital footprint can reveal disability status by proxy, and information about one's disability is sensitive personal data. Lack of understanding about the implications of processing and sharing data, including highly sensitive personal data (e.g., health, disability, and biometrics) is common. Informed consent to collect data on user behaviour is required but in practice consent is not always sought. Here is another worrying trend, where **service providers restrict the use of assistive technology features if full access to data is not granted**. For example, hearing aids or cochlear implants apps features may be limited if a user hasn't granted permission for data collection.

In relation to EU, e-health policy and connected EU initiatives, such as the EU e-health data space, it is very important to ensure that the views of persons with disabilities are taken into account. Persons with disabilities must have the right to access and control what happens to their health data; this implies the development of accessible interfaces and software that complies with existing digital accessibility standards.<sup>95</sup>

The <u>EU Data Protection Regulation</u> (GDPR) does not sufficiently protect all persons with disabilities, in that not all persons with disabilities will be able to refuse consent for processing their data. This is the case for many persons with intellectual and psychosocial disabilities because of substituted decision-making. The proposed EU regulation on Artificial Intelligence (AI) does not address this gap in the GDPR, which means that data processed by AI-systems can be done without the explicit consent who's right to object has been taken away due to guardianship.<sup>96</sup>

Even if the legal right to object to data processing by Al-systems is guaranteed, there are practical difficulties for individuals to exercise this right. It will be more difficult to know how to object to data collection or who to contact in case of a data breach by a machine. Additionally, many online services are made available to consumers only when they agree to the terms and conditions of the service, including related to data gathering. This is not a meaningful way of allowing persons to exercise control of their data. The EU Al Regulation

<sup>&</sup>lt;sup>92</sup> European Disability Forum 'Plug and Pray' report on emerging technology highlighted some of the concerns raised by persons with disabilities.

<sup>93</sup> See https://www.joedolson.com/2014/03/detecting-assistive-technology/

<sup>&</sup>lt;sup>94</sup> The European Federation of Hard of Hearing People told EDF that hearing care professionals often activate data login in hearing aids and cochlear implants without specific consent from their patients.
<sup>95</sup> Privacy and data protection related to health status and disability are especially sensitive for persons with disabilities. A person's disability can be detected by their use of assistive technology (e.g., screen-reader) when accessing a website. Revelation of one's disability or health status against their will is not only violation of the right to privacy of the person but can also lead to discrimination, for example from potential employers or service providers. It can also lead to 'algorithmic discrimination' when Artificial Intelligence-based advertisement systems for example could avoid or target persons with disabilities.

<sup>&</sup>lt;sup>96</sup> See EDF Position on Regulating Artificial Intelligence (AI) in the EU.

should ensure that when interacting with AI-based services and applications, individuals are not forced to give up their privacy in order to benefit from a service.

The Regulation also allows certain uses of AI, which are particularly intrusive against privacy and risk potential harm to persons with disabilities. These are remote biometric identification, biometric categorisation, and emotion recognition by AI systems by public authorities (e.g., law enforcement) and private entities (e.g., private companies).

#### Suggested questions:

- What will the EU do to ensure users with disabilities are adequately informed about how to protect their privacy and how to mitigate any risks associated with use of emerging technologies?
- How does the EU plan to ensure that privacy and data protection of all persons with disabilities, including all persons with intellectual and psychosocial disabilities, including those under substituted decision-making regimes such as guardianship, are protected when their data is processed by AI systems?
- What is the EU doing to prevent potentially harmful data collection by emerging technologies providers? How is the EU going to ensure that persons with disabilities are not subject to biometric categorisation and identification, as well as AI-systems?

# **Article 23: Respect for home and the family**

Persons with disabilities and families of persons with disabilities were not explicitly mentioned in the 2015 roadmap "New start to address the challenges of work-life balance faced by working families". After years of negotiation, the Work-Life Balance Directive was passed by the European Parliament in April 2019 and entered into force on 1 August 2019. The result was mixed for persons with disabilities: progress was made in several areas, such as paternity leave and recognition of family diversity. Informal carers will have a minimum of 5 days leave per year but the level of remuneration for this paid leave will be at the discretion of national governments. The concern remains that national governments set very low remuneration levels, resulting in carers' leave becoming unaffordable, as well as not raising the threshold of leave above the required minimum. This is a missed opportunity to harmonise levels of welfare across the EU and could leave many families with members who have a disability, under-protected.

The European Semester process in recent years has referred to the issue of respect for home and the family. In 2020, which was the last year to see the European Semester cycle completed (since it was suspended in 2021 because of the pandemic) the recommendations for strengthening support going to families were only present for two Member States. This was the case for <a href="Spain">Spain</a> where the Commission recommended improving the adequacy of income support for families, and <a href="Portugal">Portugal</a> where no actual recommendation was given regarding families, but where the introductory text acknowledged the importance of income support for families. All in all, support for families, and particularly the families of persons with disabilities, were not a priority for the European Commission during the Semester process.

Support to families is however foreseen as part of the EU's Child Guarantee for Vulnerable Children. Here, the EU and the Member States commit to financial support to families and

towards investing in the services they use, to bring the most vulnerable children in the EU out of poverty. See under **Article 6**.

As part of the <u>EU's Action Plan on the Pillar of Social Rights</u>, which is a commitment by the EU and all its Member States to focus more on social issues, the EU has announced its intention to create a new <u>European Care Strategy</u>. This Strategy would cover the long-term care needs for persons with disabilities across their lifespan, as well as support for families. This strategy is still in the early stages, so we will be awaiting confirmation of precisely what is foreseen for persons with disabilities and their families.

#### Suggested questions:

- How does the EU plan to address the long-term care needs of persons with disabilities, and particularly support for families of persons with disabilities, through its new European Care Strategy and in line with the CRPD?
- In what way will the Child Guarantee for Vulnerable Children support families of persons with disabilities and reduce their risk of poverty and social exclusion?

#### **Article 24: Inclusive education**

Segregated education of children with disabilities remains quite widespread in many EU Member States. In the EU, an average of 1.34% of pupils with special educational needs were enrolled in "special schools". However, for several countries the rate is much higher. Belgium, Germany, Slovakia, the Netherlands, and Latvia all have rates of enrolment in segregated schools far above the EU average. 98

Within its limited area of competence in this field, the EU uses the strategic investment of EU funds as its means for influence. Funds from the EU Social Fund allocated for social inclusion, are frequently invested in the accessibility of education settings and training of teachers and classroom assistants. Pressure is also exerted in the form of recommendations emerging from the European Semester process. However, these focus primarily on the link between education and employment, and very rarely specifically to increasing the accessibility of educational structures for learners with disabilities, including in early childhood education and care.

The EU also recently adopted the <u>Digital Education Action Plan (2021-2027</u>). This is a renewed EU policy initiative to support the sustainable and effective adaptation of the education and training systems of EU Member States to the digital age. The <u>European Commission's communication on the Action Plan</u> stresses the importance of making sure that digital education is made accessible to all learners with disabilities, but exactly how this will be achieved, and how it will include adult learners taking part in life-long learning schemes, remains unclear.

The EU Artificial Intelligence (AI) Regulation proposes to allow use of AI for determining access or assigning people to educational and vocational training institutions and assessing students in educational and vocational training institutions, and for assessing participants in

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<sup>97</sup> https://www.european-agency.org/data/cross-country-reports

<sup>&</sup>lt;sup>98</sup> European Agency for Special Needs and Inclusive Education, 2018. European Agency Statistics on Inclusive Education: 2016 Dataset Cross-Country Report

tests commonly required for admission to educational institutions. <sup>99</sup> This risks creating further barriers for persons with disabilities to access education, as it will be practically impossible for persons with disabilities to know that they were subject to AI-based discrimination and contest algorithmic decisions. Increasing use of such technologies for decision-making can amplify discrimination to mass scale and have not only personal and but societal negative implications for persons with disabilities as a 'group' (i.e., less persons with disabilities in education). Allowing use of AI for this purpose also creating tension with <u>Council Directive 2000/78/EC on equal treatment in employment and occupation</u> which aims to protect persons with disabilities, among others, from discrimination in vocational training.

The <u>Erasmus+ Programme</u> is the EU programme for Education, culture, youth and sport. It is the most successful exchange activity for students and learners in the EU. Despite its high success in the period 2014-2017 only 0,17% in the higher education strand were students with disabilities and 2,5% in the youth field. The programme provides grants dedicated to persons with disabilities. Unfortunately, in many cases students and learners with disabilities do a shorter exchange or have to go to another place than they wished for because the funding provided is not sufficient to cover disability related costs (such as sign language interpreting, personal assistant, etc.) or the university selected is not accessible. While there has been some progress with the new Erasmus+ programme, <sup>100</sup> information about the programme is not available in accessible formats and the websites and platform used are not compliant with accessibility standards. Another major barrier for students with disabilities is the impossibility to transfer the services they received in their home university to the host country. The introduction of virtual mobility component in the programme can have positive effects, however it also slows down the actions taken by national agencies to solve issues of costs and accessibility.

#### Suggested questions:

- How is the EU planning to ensure that a significant amount of funding from the EU funds will still go towards the inclusion of learners with disabilities of all ages in mainstream education settings, including digital education, particularly in light of the fact more and more EU funds will now be focused towards funding the economic recovery from the COVID-19 pandemic?
- How is the EU going to ensure that AI-systems are not used to determine persons with disabilities' access to education and vocational training?
- How is the EU planning to ensure students with disabilities of all ages can equally benefit from and participate in Erasmus+ programmes?

#### **Articles 25-26: Access to health, habilitation and rehabilitation**

It remains extremely problematic for persons with disabilities to gain access to sufficient, adapted healthcare when moving to another Member State, or even in their own country. This prevents many people from being able to enjoy freedom of movement and seek work or

<sup>99</sup> See Annex III 3 of EC proposal for Regulating Al.

<sup>&</sup>lt;sup>100</sup> For example, possibility to request grants for prefinancing and the obligation to all member states to develop their own Inclusion and Diversity strategies.

living opportunities in another EU Member State. Disability based discrimination in access to healthcare is not prohibited under EU law (see **Article 5**).<sup>101</sup>

According to the <u>Gender Equality Index 2021</u>, on average in the EU, only 19% of women with disabilities and 21% of men with disabilities perceived themselves as in good or very good health, comparing to 83% of women without disabilities and 85% of men without disabilities. At least 7% of women with disabilities and 6% of men with disabilities reported unmet needs for medical examination, comparing to 2% of women without disabilities and 2% of men without disabilities.

Beside this, there is limited to no data on access to healthcare services by persons with disabilities. Access to health is important to every person with disability and must be included in European and national research concerning the access to health services by EU citizens, including those with different types of disabilities such as intellectual and psychosocial disabilities.

#### COVID-19<sup>103</sup>

The EU's response to the COVID-19 did not sufficiently ensure the rights of persons with disabilities due to lack of consultation with organisations of persons with disabilities and lack of accessibility of public health announcement, including testing and vaccination campaigns. The coordinated actions with EU Member States, including to facilitate the supply of protective and medical equipment across Europe have not paid specific attention to persons with disabilities.

# **European Health Union**

In reaction to the COVID-19 pandemic, the European Commission took the initiative to build a <u>European Health Union</u>, in which all EU countries prepare and respond together to health crises, medical supplies are available, affordable and innovative, and countries work together to improve prevention, treatment and aftercare for diseases such as cancer.<sup>106</sup>

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Just over half of the Member States prohibit disability discrimination and require providing reasonable accommodation in the field of healthcare. A quarter of Member States only prohibit disability discrimination, but do not provide reasonable accommodation obligation, in the field of healthcare, while nearly a quarter do not have any requirement in this respect. One Member State does not prohibit disability discrimination in the field of healthcare but requires the provision of reasonable accommodation.

<sup>&</sup>lt;sup>102</sup> We note a decrease comparing to the <u>Gender Equality Index 2020</u> where 20.2% of women with disabilities and 22.8% of men with disabilities perceived themselves as in good or very good health, comparing to 83.8% of women without disabilities and 85.5% of men without disabilities.

<sup>&</sup>lt;sup>103</sup> More information is available in <u>EDF's Human Rights Report on COVID-19</u>.

<sup>&</sup>lt;sup>104</sup> The European Centre for Disease Prevention and Control (ECDC), an EU agency aimed at strengthening Europe's defences against infectious diseases, played an important role in monitoring the spread of COVID-19 and giving guidance to Member States. Despite its important role, the ECDC does not appear to have a focal point on disability and did not sufficiently consult organisations of persons with disabilities during the COVID-19 crisis.

<sup>&</sup>lt;sup>105</sup> The communication to the European Parliament and Council on '<u>Preparedness for COVID-19</u> <u>vaccination strategies and vaccine deployment</u>' adopted on 15 October 2020 made no explicit mention of persons with disabilities. On 28 October 2020, the Commission's <u>recommendation on testing</u> also completely excludes persons with disabilities.

<sup>&</sup>lt;sup>106</sup> EDF sent <u>recommendations on the European Health Union Package</u> presented in 2021, focusing on: involvement of representative organisations of persons with disabilities, right to life, equality and

For example, the Commission launched a <u>Beating Cancer Plan</u> to prevent cancer and ensure that cancer patients, survivors, their families and carers can enjoy a high quality of life. The plan includes actions and flagship initiatives covering the entire disease pathway. However, the Plan does not foresee targeted measures for persons with disabilities. If accessibility of prevention, detection, diagnosis, and treatment is not ensured, persons with disabilities will be excluded from this initiative. Women with disabilities are particularly affected when it comes to breast and uterine cancer prevention, because of this lack of accessibility to medical and radiology equipment and facilities.

#### **Cross-border healthcare**

The <u>Directive 2011/24/EU on patients' rights in cross-border health care</u> gives the right to all patients to seek healthcare in another EU Member States. In 2021, the European Commission launched an evaluation of the Directive.

Patients with disabilities continue to face barriers in accessing cross-border healthcare. In particular, the National Contact Points in charge of providing information on access to cross-border healthcare do not systematically provide accessible and targeted information to patients with disabilities. For example, on the National Contact Points' websites, no information is provided on reasonable adjustments of healthcare facilities and services, neither on sexual nor reproductive healthcare services. Few websites provide information on physical accessibility of healthcare facilities.<sup>107</sup>

In addition, EU law on cross-border healthcare include an optional provision on reimbursement of additional disability-related costs. Whether disability-related costs (e.g., increased transport costs and costs incurred by personal assistants) are reimbursed has an obvious impact on the capacity of patients with disabilities to exercise their right to planned cross-border healthcare. A previous report showed that no additional costs were reimbursed in 76% of a small sample.<sup>108</sup>

#### Suggested questions:

- How will the EU ensure that persons with disabilities benefit from the European Health Union, including Europe's Beating Cancer Plan? For example, how will it work with Member States and global partner countries to ensure that screening and treatments are accessible to persons with disabilities?
- What actions is the EU planning to foster the transposition and implementation of EU law on patients' rights in cross border healthcare, including to improve the quality of information provided to patients with disabilities on the National Contact Points' websites?
- What measures will the EU take to evaluate the access of health services by persons
  with disabilities (including in closed setting such as institutions, prisons and refugees'
  centres) and ensure that patients with disabilities are not discriminated against,

non-discrimination, preparedness and response, accessibility, data collection and EU's external actions.

<sup>&</sup>lt;sup>107</sup> More detailed information on the Directive is available in <u>EDF report on access to cross-border</u> healthcare by patients with disabilities in the EU.

<sup>&</sup>lt;sup>108</sup> IF, <u>Impact of cross-border healthcare on persons with disabilities and chronic conditions</u> (2016), 3, 15.

whether directly or indirectly, including through denial of reasonable accommodation and non-reimbursement of additional disability-related costs?

# **Article 27: Employment**

Across the EU, persons with disabilities are far less likely to be employed than persons without disabilities. The latest EU-level data is from 2019 and shows that persons with disabilities in the EU are 24.4 percentage points less likely to be employed than persons without disabilities. Only 50.8% of persons with disabilities are employed, compared to 75% of persons without disabilities. <sup>109</sup> The situation is even worse for women with disabilities. On average only 48.3% of women with disabilities are in employment. 110 The figures are even lower when looking at full-time employment with solely 20.6% of women with disabilities and 28.5% of men with disabilities working full-time. 111 Among the most affected are persons with psychosocial and intellectual disabilities and persons on the autism spectrum.

Among the major barriers faced by persons with disabilities regarding the labour market are the incompatibility of disability allowances when working (irreversible loss of allowances and being worse off in work due to the extra living costs incurred for persons with disabilities), lack of personal assistance, lack of sign language interpretation, and absence of reasonable accommodation in the workplace.

The EU has taken a number of measures to support the employment of persons with disabilities. 112 However, insufficient guidance and regulation exists on what is expected of employers when offering reasonable accommodation to workers with disabilities, as well as what support governments should give to employers. This leaves a provision of reasonable accommodation unevenly put into practice across the Member States, and means that it is easy for people in some Member States to find themselves provided with little or no adjustment in line with their needs.

Member States are also encouraged to make use of EU funds to promote employment of groups who are regularly excluded from the labour market, particularly through the use of the European Social Funds Plus. The Regulation on the use of these funds states that 25% of the money should be used by Member States to foster social inclusion, which in part requires assisting groups such as persons with disabilities into the open labour market. However, the extent to which this is done, and indeed the European Commission's ability to track how the money is being used, appear to be insufficient.

<sup>109</sup> Joint Employment Report 2021

<sup>110</sup> EU SILC 2017

<sup>&</sup>lt;sup>111</sup> Gender Equality Index 2020, Work

<sup>&</sup>lt;sup>112</sup> For example, the EU has invested directly in projects to assist in the integration of persons with disabilities into the labour market, notably using the EU Social Fund. The EU also facilitates, by means of an EU Regulation, the use of State Aid in the Member States to support inclusive employment, subsidise wages and provide reasonable accommodation. The General Block Exemption Regulation (EU) No 651/2014 declares certain this category of aid compatible with the internal market in application of Articles 107 and 108 of the Treaty on the Functioning of the EU. Finally, the EU Directive (Council Directive 2000/78/EC) establishes a general framework for equal treatment in employment, vocational guidance, and training.

#### Pay transparency

Salary disparities remain and persons with disabilities stay unemployed or face in-work poverty. Women with disabilities are even more at risk as they face both a gender and disability pay gap. According to the <u>Gender Equality Index 2021</u>, the average of the mean monthly earning in purchasing power standard<sup>113</sup> of women with disabilities is 1.859 comparing to 2.436 for men with disabilities, 1.981 for women without disabilities and 2.652 for men without disabilities.

In 2021, the European Commission made a proposal for a <u>Directive on pay transparency</u> to combat the gender pay gap. The proposal did not foresee the collection of data and statistics disaggregated by disability and lacks an intersectional approach (crossing gender and disability) and does not require that information on pay transparency is made available to all persons with disabilities in a variety of accessible communication and formats, including easy to read and accessible digital documents.<sup>114</sup>

#### **Adequate Minimum Wage**

The EU is in the process of adopting a <u>Directive on adequate minimum wage</u>. Persons with disabilities are all too often paid below national or sectoral minimum wage thresholds. This is particularly problematic in certain sheltered workshop settings where workers are not given the legal status of employees and therefore do not have the same rights regarding wages, social protection, paid sick leave etc.

The disability movement hopes that the negotiations around the Directive will result in better protection for workers with disabilities in the EU and will improve their ability to avoid in-work poverty.

# Risk of algorithmic discrimination in employment

The EU Artificial Intelligence (AI) Regulation proposes to allow use of AI for recruitment, selection, promotion, and termination decisions in employment.<sup>115</sup> Use of AI-based recruitment tools have already proved to be discriminatory towards persons with disabilities, and members of other marginalised groups.<sup>116</sup> In this sense, persons with disabilities can be

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<sup>&</sup>lt;sup>113</sup> The mean monthly earning, besides earnings from paid work, includes pensions, investments, benefits, and any other source of income. It is expressed in the purchasing power standard (PPS), which is an artificial currency that accounts for differences in price levels between Member States.

<sup>&</sup>lt;sup>114</sup> See EDF proposals for amendments to the Pay Transparency Directive

<sup>&</sup>lt;sup>115</sup> See Annex III 4 of EC proposal for Regulating AI.

and Unilever, was found to massively discriminate against many persons with disabilities who have out of the 'norm' facial expressions and voice. Among others, this affected Deaf, blind, and Deafblind persons, as well as those with speech impairments and people who survived a stroke. Al systems are widely deployed in the US to use personality characteristics as a signal of job success for specific kinds of roles, even though studies have shown they have no correlation with job performance. These tests tend to disproportionately screen out people with disabilities, specifically persons with psychosocial disabilities. Al-based application screening tools often negatively score gaps in candidates' employment. This can result in a lower score for a candidate with disability who might have taken a break from work due to health reasons. Gaps in employment is a proxy that also tends to discriminate against women (connected to having children), which means women with disabilities are even at greater risk of being discriminated as women and as persons with disabilities. Persons with disabilities who have intersecting identities, for example trans\* persons with disabilities, are also

subject to intersectional discrimination even if it is not based on their disability.<sup>117</sup> Allowing use of AI for job recruitment purposes, risks amplifying already disproportionately high unemployment (and poverty) rates for persons with disabilities in the EU and jeopardising the aim of Directive 2000/78/EC protecting persons with disabilities, among others, from discrimination in employment. Given that job candidates often will not even be aware that they were subject to discriminatory algorithmic assessment, enforcing the Directive will become extremely difficult.

# **European Solidarity Corps**

The <u>European Solidarity Corps programme</u> gives the opportunity to young people between 18 and 30 to take part in projects that benefit communities, either abroad or in their own country. These projects offer an inspiring and empowering experience, as well as the chance to bring change while developing skills and competences. Unfortunately, young people with disabilities who wish to take part in the programme continue to face barriers. For example, volunteers with disabilities who leave their country for a longer period than 1 year may be obliged to give up their disability allowances (e.g., in France).

## Suggested questions:

- What measures will the EU take to promote the employment of all persons with disabilities, including of women with disabilities and combat the gender and equality pay gap they face, including through the proposed Directive on Pay Transparency?
- How will the proposed EU Directive on Minimum Wage help reduce pay disparities between persons with and without disabilities in the EU, and how will it foster better quality of life and social protection for workers with disabilities?
- How is the EU going to ensure that AI systems are not used for determining persons with disabilities' access to employment?

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

EU data reveals that being a person with disabilities in the EU significantly increases the risk of experiencing poverty and social exclusion. EU figures suggest that 28.4% of all persons with disabilities currently live in poverty and experience social exclusion. Persons with disabilities are shown to face a higher risk of poverty and social exclusion than the general population in all 28 Member States and even more so for women with disabilities.

Furthermore, austerity following the financial crisis has been shown to have an effect on poverty rates of persons with disabilities in several Member States, as well as the situation on non-take-up of services and benefits. Eleven countries showed an increase in poverty rates since 2010, including countries that generally performed quite well during the crisis, such as Luxembourg, Germany, and Sweden. Not only are persons with disabilities poorer,

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subject to discrimination risk even if not on the ground of disability, as in <a href="the case of Uber suspending trans">the case of Uber suspending trans</a> drivers' accounts. The Uber security feature that required drivers to take a selfie to verify their identity. If the photo did not match to other photos on file, it was flagged, and driver's account was suspended. This type of security software can also discriminate against a person who acquired a scar due to a burn, for example, or has undergone a facial reconstruction surgery.

<sup>&</sup>lt;sup>117</sup> See EDF position paper on Regulating Artificial Intelligence (AI) in the EU.

<sup>&</sup>lt;sup>118</sup> EU SILC 2019

<sup>&</sup>lt;sup>119</sup> Including the United Kingdom at the time of creating this report.

but they also face extra costs from living in a society that is not adapted to them: disability-related costs estimated at 23,012 euros/year in Sweden or 14,550 euros/year in Belgium, for example.<sup>120</sup>

#### Suggested question:

- What does the EU see as the best mechanisms to bring people out of poverty, and how has it ensured that particular focus is given to supporting persons with disabilities in escaping poverty?
- How does the EU plan to ensure that EU funding will help bring persons with disabilities out of poverty and how will it monitor the effectiveness of how the funds are used?

# Article 29: Participation in political and public life

The EU Treaty and the EU Charter on Fundamental Rights recognise the right of persons with disabilities to be free from discrimination in exercising their citizenship rights, including the right to vote and stand for elections. The European Court of Justice confirmed that Member States enjoy a wide margin of appreciation in imposing conditions on the right to vote. However, those conditions may not curtail the right to vote to such an extent as to impair its very essence. Still, persons with disabilities face a series of legal and practical barriers that prevent them from exercising their right to participation in political and public life on an equal basis with others.

According to the most recent data by the <u>European Economic and Social Committee</u>, approximately 400,000 persons with disabilities are deprived from their right to vote in 14 Member States, <sup>122</sup> and in each of the 27 EU countries, there are rules or organisational arrangements that deprive some voters with disabilities of the possibility of participating in European Parliament elections on an equal basis with others. Additionally, only 7 EU countries guarantee the right of all persons with disabilities to stand as candidates in the European Parliament elections. <sup>123</sup>

In 2020, the European Parliament launched a resolution <u>proposing a reform of the European Union (EU) electoral law of 1976</u>. It is an important opportunity to make the EU Parliament elections more accessible and inclusive of EU citizens with disabilities. However, it is not yet certain whether the Member States in the Council will agree with such proposal and how the new regulation will ensure that all EU citizens with disabilities can vote, including by increasing the accessibility of the EU elections which are arranged at national level.

<sup>&</sup>lt;sup>120</sup> Antón, J.I., Braña. F.J. and Muñoz de Bustillo, R. (2014). <u>An analysis of the cost of disability across</u> Europe using the standar<u>d of living approach</u>.

<sup>&</sup>lt;sup>121</sup> See for example: Sitaropoulos and Giakoumopoulos v. Greece [GC], 2012.

<sup>&</sup>lt;sup>122</sup> In 8 Member States certain persons with disabilities are automatically excluded from political participation and thus denied the right to vote. This is the case in Bulgaria, Cyprus, Estonia, Greece, Lithuania, Luxembourg, Poland, and Romania. In 6 countries, placing a person under guardianship does not automatically mean the loss of voting rights, but the court or authority taking the decision to place somebody under guardianship may also decide to restrict the voting rights. This may happen in Belgium, the Czech Republic, Hungary, Malta, Portugal, and Slovenia. Positively, recent progress in implementing the CRPD increased the number of countries in which under no circumstances may an individual be deprived of the right to vote. These 13 Member States are Austria, Croatia, Denmark, Finland, France, Germany, Ireland, Italy, Latvia, the Netherlands, Slovakia, Spain, and Sweden.

Persons with disabilities are not sufficiently represented among policy makers. Among the 705 Members of the European Parliament, there are only four members with a visible disability.

Regarding participation in public life, in 2021 the three main EU institutions (Commission, Parliament and Council) launched a joined democratic initiative known as the Conference on the Future of Europe. The main goal of the Conference is to gather the views and ideas of EU citizens on the future they envisaged for the EU. The ways to participate in the Conference are through a digital platform which is not accessible (more information on Part 2 - Article 29), and the participation of randomly selected citizens who will debate in panels the different proposals received through the platform. Different civil society organisations, including EDF, have raised the lack of diversity in the citizens panels (which were selected through random phone calls).

#### Suggested questions:

- How does the EU plan to support the right to vote and stand as a candidate to persons with disabilities in European elections?
- How will the EU ensure the accessibility of European elections for all persons with disabilities?
- What actions have and will the EU take to ensure the participation of persons with disabilities in EU public affairs discussions, such as the Conference on the Future of Europe?

# Article 30: Participation in cultural life, recreation, leisure, and sport access to culture

On 1 October 2018, the EU ratified the Marrakesh Treaty to Facilitate Access to Published Works by Visually Impaired Persons and Persons with Print Disabilities in order to grant certain copyright exemptions to create accessible versions of print media such as e-books.

The EU has made a step forward toward strengthening legal obligation of States to ensure accessibility of televised broadcasts and on-demand services through the revised Audiovisual Media Services Directive adopted in November 2018. Countries must ensure that media service providers under their jurisdictions make their audiovisual content continuously and progressively more accessible to persons with disabilities through proportionate measures. However, it does not prescribe any timelines, or qualitative and quantitative targets to reach this goal, nor does it require Member States to do this. 124 Ambiguity of the EU legal text risks to lead to different levels of accessibility among Member States. This is especially unfortunate, as state of the art international standards for ensuring accessibility of audiovisual content exist. 125

<sup>124</sup> The Directive only requires Member States to encourage action plans developed by service providers to achieve accessibility and leaves the concrete steps and timelines to achieve this to the will of the service providers.

<sup>&</sup>lt;sup>125</sup> During the transposition EDF has tried to advocate for obligatory quotas and quality standards for audiovisual content prescribed by national law. See EDF toolkit on transposition of the AVMSD.

In the absence of EU legislation on accessibility of the built environment, <sup>126</sup> persons with disabilities continue to face barriers to accessing places of cultural performance and services, sites of cultural importance, as well as recreational, leisure and sports facilities. This access barrier also means that persons with disabilities are kept from developing and utilising their creative, artistic, and intellectual potential for the benefit of the whole society and participating in sports activities not only as spectators but also as players. While the planned European Disability Card<sup>127</sup> will most likely include reduced entry price or other reductions for persons with disabilities, it will not directly address the issue of lack of accessibility.

The EU also has several initiatives related to culture, such as the European Capital of Culture or the EU Prize for Contemporary Architecture (Mies van der Rohe Awards). Those initiatives currently do not mainstream the inclusion of persons with disabilities. <sup>128</sup> In addition, fundings available under the <u>Creative Europe programme</u> missed the opportunity to mainstream disability and monitor the impact of EU-funded cultural projects on persons with disabilities.

# Suggested questions:

- Noting that the EU Audiovisual Media Services Directive (AVMSD) does not prescribe
  minimum quotas and quality standards for the provision of access services by
  television broadcasters and on-demand services in the EU, how is the EU planning to
  ensure persons with disabilities have equitable access to audiovisual content?
- How will the EU ensure the accessible and safe participation of persons with disabilities in cultural life across its Member States, including access to cultural performances and services, sites of cultural significance, as well as other recreational, sports, and leisure facilities? In this regard, what actions are taken by the EU to monitor the effective implementation of the Marrakesh Treaty by the Member States?
- How will the EU ensure that its initiatives, prizes, and programmes (including funding programmes) concerning culture and sport are accessible and fully aligned with the CRPD?

#### Article 31: Statistics and data collection

<u>Eurostat</u> is the statistical office of the EU. Among its key objectives we see that of "providing statistics on key areas of social policy where the citizens are the centre of the interest" (Objective 3.2.1). Disability is identified as an area within this objective. All data must be

<sup>128</sup> Unlike the New European Bauhaus Prizes.

<sup>&</sup>lt;sup>126</sup> As noted under Article 9, the European Accessibility Act does not ensure accessibility of the built environment, because transposing the relevant built environment requirements (Annex III) are voluntary for Member States. Only if those are transposed in national legislation they will need to be complied with. However, there is little motivation from most Member States to go beyond what the Act requires them, and even if some Member States do it (and others do not) this will create a fragmented picture for accessibility of the built environment for persons with disabilities.

<sup>&</sup>lt;sup>127</sup> See under article 18 in the report.

The programme is governed by Regulation No. 99/2013 of the Parliament and the Council of 15 January 2013 on the European statistical programme. It has been extended to 2020 by Regulation (EU) 1951/2017 2017/1951 of the European Parliament and of the Council of 25 October 2017.

disaggregated by gender. The <u>EU Statistics on income and living conditions</u> (EU-SILC) show how affected persons with disabilities are by the issue of poverty and social exclusion, and educational attainment. It is disaggregated according to persons with "some" or "severe" limitations, all of whom are classed as having a disability. The data falls short of disaggregating by type of disability, something that would be afforded by data collection techniques such as the <u>Washington Group Short Set of Questions</u>. It also misses from its scope persons with disabilities living in institutions, as it only reaches people living in households, which does not include residential and institutional care. Therefore, we almost entirely lack adequate data on persons with disabilities living in institutions.

An important issue faced concerning the data collected by Eurostat is that they are based on the statistics produced at national level and that Member States do not agree on a common approach to disability.

# Data on employment

The <u>European Union Labour Force Survey</u> shows employment figures for people living in the EU. Data on workers with disabilities is occasionally collected as part of this process. Recently the EU stepped up its commitment to monitoring the employment of persons with disabilities by making the "Disability Employment Gap" a new indicator in its <u>EU Social Scoreboard</u>, a tool to monitor social progress across the EU and have up-to-date data on a list of social issues. This should allow to better monitor barriers to the labour market for persons with disabilities compared to persons without disabilities. However, we still lack more detailed disaggregated data, also cross-referencing gender, that would allow us to distinguish the impact of type of disability on employment rates. It also rules out the possibility of understanding the barriers attached to persons with multiple disabilities.

# Data on women and girls with disabilities

Data and statistics about women and girls with disabilities is also missing. The **European Institute for Gender Equality** (EIGE) started to disaggregate some of the data of its Gender Equality Index by disability. Unfortunately some important areas are not covered, notably in relation to <u>power</u> (decision-making positions across the political, economic and social spheres) and <u>violence</u> against women. In addition, there is very limited analysis of the situation of women and girls with disabilities in EU partner countries. Inclusive and intersectional data are not being collected by EU's external action services and the EU delegations.

#### Data in international relations and disaster risk reduction

The latest version of DG ECHO partners' reporting guidelines encourages the use of the Washington Group Short Set of questions in data disaggregation. However, this is not obligatory and there is no reporting indicator that would measure its degree of implementation. Similarly, risk assessment or disaster lost data gathered within the EU by the EU <u>Disaster Risk Management Knowledge Centre</u> (DRMKC) or the EU <u>Joint Research Centre</u> (JRC) is not routinely disaggregated by disability. In 2016, during development of the Sendai framework Indicators, the EU Joint Research Centre position was that this was not a reasonable aim to have, with the resources available.

Other EU bodies also fail to disaggregate data by disability. For example, the **European Centre for Disease Prevention and Control** (ECDC),<sup>130</sup> in charge of the regular monitoring of the COVID-19 pandemic in the EU, failed to provide statistics on persons with disabilities (while data was disaggregated by age and gender).

Besides, the European Union has not developed any human-rights based indicators system to report on its CRPD obligations. Only the **Fundamental Rights Agency** has issued indicators to assess political participation of persons with disabilities as a one-off exercise in 2014.<sup>131</sup> Also, the European Sustainable Development Goals (SDGs) sets of indicators are not aligned with the internationally agreed ones, implying that comparison is difficult.

Finally, there has been no major event or campaign aiming to disseminate the available data and understanding of the living situation of persons with disabilities, except for the publication of the reports on the <u>website of the Academic Network of European Disability Experts</u>. The Commission is continuing to invest in research through the European Disability Expertise project, which will see new research published in a designated webpage. The first areas of research will be the impact of COVID-19 on persons with disabilities and accessible technology.

### Suggested questions:

- What steps is the EU going to take to align its data collection to the Sustainable Development Goals and disaggregate data also by disability, using the Washington Group Set of Questions and to put in place a comprehensive human rights-based indicators system to track progress of the EU against the implementation of its CRPD obligations?
- What data collection efforts will the EU undertake to address the major gaps in availability, reliability and comparability of data relating to the living conditions of persons with disabilities in Europe, including on women with disabilities, children, and older persons with disabilities and on people living in institutions?
- How does the EU propose to make use of its data collection on employment as part
  of the Social Scoreboard to give policy recommendations to the Member States as
  part of the European Semester process?
- In what ways does the EU plan to extend data collection on disability within the Social Scoreboard to go beyond merely collecting data on employment rates?

#### **Article 32: International cooperation**

Regarding its global work in the world, the EU has not adopted a harmonised policy related to promoting and respecting the rights of persons with disabilities. It is unclear how this issue included in the EU Disability Rights Strategy will be implemented, with no resources allocated, no timeframe, no detail how it will support partner countries and monitor its progress.

<sup>130</sup> Agency of the European Union aimed at strengthening Europe's defences against infectious

<sup>&</sup>lt;sup>131</sup> EU Fundamental Rights Agency, The right to political participation for persons with disabilities: human rights indicators, 2014

Regarding its global work and the Sustainable Development Goals (SDGs), the EU has adopted a <u>new European Consensus on Development</u> in June 2017. The Consensus set out a new framework for development cooperation for the EU and its Member States. The document was considered a direct response by the EU to the SDGs. Since its publication, the EU has not followed-up or adopted any policy on how to implement the SDGs to leave no one behind both in the EU Member States and in its global work.

Regarding the EU diplomatic missions, information, training and guidance should be given to all relevant staff located within the 140 delegations of the EU in the world. Partners must also become familiar with the CRPD while a real dialogue and consultation should start with national representative organisations of persons with disabilities. So far, we don't have any clear activities and timeframe on how the EU is practically promoting the inclusion of persons with disabilities and support the implementation of the CRPD in the world.

#### Suggested questions:

- What steps will the EU take to adopt an EU Disability Action Plan on its global work to promote the rights of persons with disabilities and to ensure that all its development and humanitarian aid programming is CRPD compliant (e.g., Action Plans have already been created for gender and human rights and democracy<sup>132</sup>)?
- What plans does the EU have to properly assign a disability focal point focusing on disability-inclusive international cooperation that would provide for guidance and training on CRPD implementation to the 140 delegations of the EU in the world, and have sufficient human and financial resources to do so?
- What plans does the EU have to train and build the capacity of EU staff (including the EU focal point, EU delegations, Directorate-General on European Civil Protection and Humanitarian Aid Operations field staff), and for EU Member State agencies in partner countries, on the CRPD implementation, also by involving representative organisations of persons with disabilities?

### **Article 33: Implementation and monitoring**

The EU did not designate CRPD focal points in all institutions, bodies, and agencies. The implementation of the CRPD falls under the mandate of the EU Commissioner for Equality who is part of the Directorate-General on Justice. However, the daily implementation of the Convention is still being led by the Unit on Disability and Inclusion in the Directorate-General (DG) on Employment.

EDF has been calling for the establishment of a CRPD unit under the mandate of DG Justice, which also works on other areas of equality and disadvantaged groups, to ensure coordination of CRPD implementation across the Commission services. This CRPD unit is still missing from the EU's approach. While the new Strategy on Disability Rights does pay attention to mainstreaming (such as committing to systematic references to the CRPD in all relevant policy fields or staff training on disability rights), without strengthened human and financial resources within the Commission, or the establishment of a strong and influential

<sup>&</sup>lt;sup>132</sup> The <u>EU Gender Action Plan III</u> 2021-2025 and the <u>EU Action Plan on Human Rights and Democracy 2020-2024</u>

CRPD focal point higher in the hierarchy of the Commission, it is hard to see how this will be achieved.

In addition, the EU has not yet established an inter-institutional mechanism for the coordination of the implementation of the Convention between the Commission, the Parliament and the Council, and all relevant EU agencies and bodies. The Council is totally lacking any kind of internal coordination mechanism for the implementation of the CRPD. Organisations of persons with disabilities are completely excluded from the decision-making procedure at the level of the Council which means monitoring is very difficult.

As announced in the Disability Rights Strategy, the European Commission transformed the Disability High-Level Group into the new <u>Disability Platform</u>, which had its first meeting in December 2021. The Platform is chaired by the Commission services in DG Employment, supported by the Disability unit as its secretariat, and its members are the CRPD focal points of the Member States, and civil society organisations. The call for organisations, nevertheless, did not follow the General Comment 7, and put at the same level representative organisations of persons with disabilities, service providers associations, and other civil society organisations. The Platform will adopt an annual work programme and will consult its members on the flagship initiatives of the Strategy. However, it is yet not clear how the Platform will monitor the implementation of the Strategy and how it will ensure coordination with other EU institutions such as the EU Parliament and the Council of the EU

Regarding coordination, the Disability Rights Strategy announced the appointment of "disability coordinators" within the services of the Commission and encouraged other EU institutions to create such position. At the time of drafting this report, we do not know to which extent this action has been fulfilled and how the disability coordinators will cooperate among them.

Since 2016, the CRPD Independent Monitoring Framework is composed of the European Parliament (Petitions committee receiving complaints from citizens, but also the Employment and Social Affairs committee and the Civil Liberties committee), the Fundamental Rights Agency of the European Union (FRA), the European Ombudsman and EDF. The functioning of the Framework will be evaluated by the European Commission in 2022.

#### Suggested questions:

- Under which timeframe will the EU establish a CRPD Unit and designate focal points in all institutions, bodies, and agencies?
- What inter-institutional mechanism will the EU put in place for the coordination of the implementation of the Convention between the Commission, the Parliament, and the Council? And what action will the Council take to become more transparent to allow for better scrutiny from organisations representing persons with disabilities?
- Have all EU institutions and bodies appointed a "disability coordinator" as suggested in the EU Disability Rights Strategy? Can the European Commission explain how these coordinators will cooperate?

# Part 2: European Union institutions' compliance with the Convention (as public administrations)

# **Articles 1 and 2: purpose and definitions**

The <u>EU Staff Regulations<sup>133</sup></u> include a definition<sup>134</sup> of disability and reasonable accommodation, as well as the concept of positive action<sup>135</sup> that comply with the CRPD. However, that definition of disability has not been transposed into other EU internal instruments, such as the the Joint Sickness Insurance Scheme (JSIS) (see **Article 25**).

Although the definition of a person with disability complies with the CRPD, the EU system continues to rely on medical evaluations. There is a medical examination and an evaluation to assess if the person is physically and mentally "fit" to perform their duties. There is also an invalidity committee formed exclusively of doctors which evaluates professional invalidity. The example of the example of the exclusive of doctors which evaluates professional invalidity.

#### Suggested question:

 What steps will the EU take to ensure that all internal instruments, policies, and practices of the EU institutions are revised to include the human rights approach to disability as laid down in Article 2 CRPD, and as included in the Staff Regulations?

# **Article 4: General obligations**

The EU institutions do not have a comprehensive and cross-institutional strategy on how to implement the CRPD internally for their staff and visitors.

The 2021-2030 EU Disability Strategy includes some actions to "lead by example" inside the EU institutions. These proposed actions concern:

- the adoption of a new human resources strategy that will include actions to promote diversity and inclusion of persons with disabilities in the European Commission<sup>138</sup>
- actions to improve accessibility of communication and buildings (a caveat being the "urban planning requirements of the host countries")<sup>139</sup>

<sup>&</sup>lt;sup>133</sup> See Regulation (EEC, Euratom, ECSC) No 259/68 of the Council, as amended by <u>Regulation (EU, Euratom)</u> No 1023/2013 of the European Parliament and of the Council.

<sup>&</sup>lt;sup>134</sup> See article 1d(4) of the Regulations.

<sup>&</sup>lt;sup>135</sup> The implementation of positive actions for persons with disabilities still requires improvement. Only inequalities relating *de facto* to women are explicitly mentioned in the Staff Regulations. According to the Commission, this does not prevent positive measures relating to persons with disabilities but neither does it require such measures: "Although not expressly required by the Staff Regulations, some institutions have also adopted implementing rules on the following matters dealt with in Title I of the Staff Regulations: equal opportunities, disability, measures of a social nature, health and safety standards and transfer. (COM/2021/258 final).

<sup>&</sup>lt;sup>136</sup> See article 28e, chapter 3 article 12.2e, chapter 3 article 82.2e, chapter 3 article 128.2d of the regulation.

<sup>&</sup>lt;sup>137</sup> See article 33

<sup>&</sup>lt;sup>138</sup> Section 8.1 of the strategy - but no further information is available as to how it should look like. The European Parliament for example has not provided a new human resources policy yet. <sup>139</sup> Section 8.2 of the strategy

- support for the implementation of the Action Plan Educational Support and Inclusive Education of the European schools<sup>140</sup>
- a call on all EU institutions and bodies, agencies, and delegations to designate disability coordinators for their institutions and for their disability strategies

The Disability Support Groups in the European Commission, the Council of the European Union and the European Parliament bring together staff concerned with disability, either staff with disabilities or staff who are carers of persons with disabilities. These groups are not appropriately consulted or involved in a systematic way in the development of internal instruments and policies to implement the CRPD. Their views are also not systematically taken into account. Moreover, these support groups are not allocated the resources they need, and they are overloaded with requests for advice and support which the responsible EU institutions' services also find difficulties in coping with.

The European Parliament lacks an internal focal point designed to make decision-making more holistic and more effective although it called for it in numerous own resolutions.<sup>142</sup>

#### Suggested question:

- What steps will the EU take to adopt a strategy to realise the CRPD within all EU
  institutions, bodies, and agencies, and how will it ensure the close involvement and
  active consultation in a systematic way of the staff with disabilities and staff who are
  carers of persons with disabilities in the design, implementation, and evaluation of the
  strategy? What budget and timeline will the strategy take?
- What governance and coordination structures, such as focal points in all institutions, agencies, and relevant Directorates-General, will be put in place for the creation, implementation, coordination and monitoring of the strategy within institutions and agencies, and between them? What are the commitments and state of play across the board? Who is responsible for following up on the situation centrally and in real time?

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<sup>&</sup>lt;sup>140</sup> Section 5.3 of the strategy

<sup>&</sup>lt;sup>141</sup> An example of lack of consultation is the 'Autism Spectrum Disorder: Summary Sheet' adopted in 2020 by the Inter-Institutional Medical Council of the EU Institutions in relation to the reimbursement of expenses for "therapy and Autism spectrum disorders". The Medical Council restricted the recognition as "serious illness" and the corresponding ceiling of reimbursement to a limited number of cases of autism. It was reported that it had far-reaching implications EU institutions staff carers and their dependents on the autism spectrum, primarily children. The process that led to the adoption of the Medical Council's Opinion lacked transparency and there was no prior consultation with the staff groups representing persons with disabilities. It should also be noted that autism should be considered as a disability and not an illness.

<sup>&</sup>lt;sup>142</sup> See resolutions <u>2015/2258(INI)</u>, <u>2017/2127(INI)</u> and <u>2019/2975(RSP)</u>, as well as Report on the Equal Employment Directive <u>2020/2086(INI)</u> of March 2021 (pt. 39) and Report on the protection of persons with disabilities through petitions: lessons learnt <u>2020/2209(INI)</u> of June 2021. and June 2020, plus the Langensiepen Report on the Equal Employment Directive of March 2021 (pt. 39) and the Agius Saliba Report on the protection of persons with disabilities through petitions: lessons learnt, June 2021

# **Article 5: Equality and non-discrimination**

The provision of reasonable accommodation to employees with disabilities and those caring for persons with disabilities remains an issue.

Although failure to provide reasonable accommodation may be considered a form of disability discrimination, including discrimination based on association with a person with disabilities (as in the case of carers), the EU institutions do not consider that a reasonable accommodation policy needs to be established for carers. There are different measures in place for staff who are carers, but there is no systematic approach, and they are applied to different degrees in the different institutions.

During the COVID-19 pandemic, there has been limited coordination of the necessary reasonable accommodation measures.<sup>143</sup>

#### Suggested question:

 What steps has the EU taken to adopt a policy on reasonable accommodation in the workplace for all EU employees with disabilities and employees caring for persons with disabilities, including teleworking?

# **Article 9: Accessibility**

The accessibility of almost every EU institutions' building falls short of international and European accessibility standards. Despite an audit-based recommendation in 2003 for all institutions to develop standards above local requirements, only the European Commission has very recently adopted guidelines ridden with exceptions for accessibility requirements, and the European Parliament is preparing new guidelines. In a few cases only has accessibility been considered from design to delivery. Major works to refit any buildings to bring them to the level of European or international standards have not taken place yet

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<sup>&</sup>lt;sup>143</sup> In the European Parliament, it was reported cases of staff with long-term health conditions, or those with family members at higher risk to COVID-19 or its health or socioeconomic consequences, not initially being granted any accommodation to decrease their risk of exposure or other health or socioeconomic consequences of the pandemic. Some of these gaps are related to pre-crisis requirements for permission to telework in the Parliament staff regulations. For instance, before teleworking became mandatory for all staff, a request for teleworking would not necessarily be possible for parents whose child is in palliative care outside the home, hospitalised, or institutionalised, or for a staff member living with a person who is recognised as vulnerable but is not a direct relative. Further concerns on reasonable accommodation were raised in terms of teleworking, which has not been officially recognised as an area where reasonable accommodation apply, and return-to-work policies. Special COVID measures to support staff and carers kicked in extremely late, due to missing structures, i.e. focal point.

<sup>&</sup>lt;sup>144</sup> Projektbüro Mobilität und Verkehr (Prof. Dr.rer.nat. habil. Wilfried Echterhoff) Studie Über Den Zugang Von Behinderten Menschen zu den Europäischen Institutionen, Abschlussbericht vom 31. August 2003. Europäisches Parlament Abteilung Gebäudeverwaltung L-2929 Luxemburg. Vergabenummer: 2002/S 193-151877.

European Commission Office for Infrastructure and Logistics in Brussels Manual of Standard Building Specifications Version 05/04/2019 v1.1: Improvements in the performance of renovated buildings (partial or major renovation, etc.) or redeveloped buildings must be appropriate, consistent and proportionate to the scope of the work, taking into account any existing legal, functional, technical and budgetary constraints and deadlines. Both the caveats and the limited scope of accessibility requirements make this fall short of the CRPD Committee's General Comment No 2 on Article 9, Accessibility.

although, in France, works required by new legislation must be and will be undertaken by the European Parliament.

The interservice working group on accessibility responsible for accessibility questions in the European Parliament was first terminated and only recently reanimated. The Parliament's Brussels Hemicycle and Committee rooms are inaccessible for wheelchair users. Pop-up constructions are required for high-level speakers in the Brussels hemicycle. In Strasbourg's Hemicycle, wheelchair users can only attend the meetings in the last row of the room and cannot access the podium safely or at all.

EU offices in some EU Member States are accessible to visitors and/or staff, while other are not. In general, persons with disabilities have little knowledge of EU offices, their activities, and events.

Consultations, events and activities organised by the EU institutions often are inaccessible to persons with disabilities. The Commission's online public consultation platform "Have your Say" is not accessible. This creates barriers for participation in EU policy-making both for persons with disabilities as individuals, as well as for organisations of persons with disabilities. This is also the case for workshops and meetings organised by different services of the European Commission and structures related to the Commission 146.147 Questions asking participants their requirements for access services such as live captioning or sign interpretation are not asked in event registration forms by default. Often video conference platforms that are not the most accessible for persons with disabilities (e.g., "WebEx)" and interactive tools (e.g., mural) are used which are not accessible for all persons with disabilities.

The European Commission's decision to add an authentication process using 'EUlogin' for citizens to respond to online public consultation currently creates accessibility barriers preventing people with disabilities from responding. The process requires setting up of an account, which involves solving a CAPTCHA, without alternative options to connect and/or participate in survey. This is a well-known accessibility barrier for many. Security features should not compromise the accessibility of online processes.

There are inaccessible computer applications in use inside of the institutions that make it impossible for persons with disabilities using assistive technologies such as screen reader users, to access at all, or on an equal basis, certain major professions, jobs, or outsourced tasks.

# Suggested questions:

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<sup>&</sup>lt;sup>145</sup> Contrary to the Commission's procurement guidelines which state that "for event organisation, the conference building should be accessible and the information should be accessible to all (e.g. sign language translator)." VADE-MECUM on Public Procurement in the Commission (updated January 2020).

<sup>&</sup>lt;sup>146</sup> This also included the 'AGM' platform used by the European Commission for expert meetings, which is inaccessible.

<sup>147</sup> For example, the regular meetings of the Multi-Stakeholder Platform on ICT standardisation, which was set up by a Commission decision to advise on matters related to the implementation of ICT standardisation policies, do not provide access services such as captioning or sign language interpretation.

- What initiatives will the EU take to ensure that its buildings, information, communication, events, activities, procedures, application, and administrative tools are accessible to all persons with disabilities? What plan of action will it draft, and budget will it allocate to this goal?
- When will the EU amend its online consultation tool and processes to ensure these are fully accessible to citizens with disabilities? Will this include the provision of Easy-To-Read formats for online consultations?

# **Article 13: Access to justice**

Contrary to the recommendation from the CRPD Committee in 2015, the Court of Justice of the European Union does not guarantee full access to justice to persons with disabilities, including those deprived of their legal capacity. Physical and procedural barriers still exist for persons with disabilities, including those who might wish to work in the court as lawyers, clerks, etc. Persons with disabilities cannot play an active part in the EU justice system.

#### Suggested question:

 What steps will the EU take to ensure that its justice system is fully accessible to all persons with disabilities?

# Article 21: Freedom of expression and opinion, and access to information

The <u>EU Web Accessibility Directive</u> establishes rules to ensure improved accessibility of the websites and mobile applications of public bodies in the EU Member States to persons with disabilities. Although this Directive applies only to Member States, the EU institutions are encouraged to comply with its requirements.

The European Ombudsman opened an own-initiative inquiry regarding the inaccessibility of the European Commission's public websites, including the online tool for registering to participate in expert meetings and online platforms hosted by the Commission to facilitate policy debates. A decision was taken in 2018 with six recommendations for the European Commission to implement, such as the adoption of an action plan on web accessibility, compliance with the latest international web accessibility standards, mandatory training for its staff, putting 'accessibility statements' on its website, and improving the accessibility of the JSIS online internal web tool. That action plan was never presented but was included in the European Disability Rights Strategy to be launched in 2021. At the time of drafting this report this digital accessibility plan has not been released yet, and European disability organisations have not been consulted about it.

In 2019, Siteimprove released the report "<u>Democracy, Digital Accessibility and the European Union</u>" with foreword of the European Disability Forum. The report identified the European Parliament's website as the website with worst accessibility compared with all websites of national parliaments.

Capacity-building and training materials, public campaigns, statements, and other documents published by the European Union institutions are often not available in accessible formats. For example, at the beginning of the COVID-19 pandemic the EU leaders made a series of public and high-level statements to Europeans about the pandemic and failed to ensure these statements were accessible to persons with disabilities with interpretation in International Sign, captioning, and Easy-to-Read information. This has been rectified after

advocacy from the disability community. However, in general, statements by EU Commissioners are seldom accessible to Deaf and hard of hearing people and little information is available in Easy-to-Read format.

In addition, the procedure to create a profile on the <u>Commission's Portal for Funding and Tenders</u> is inaccessible to Blind and partly sighted people using screen readers. This directly excludes them from opportunities to contribute to the creation of more equal and inclusive society.

#### Suggested questions:

- What steps has the EU taken to implement the recommendations from the European Ombudsman, and to ensure that all EU institutions, bodies, and agencies follow the obligations of the Web Accessibility Directive?
- What measures will the EU take to ensure that its communication with EU citizens is accessible to those with disabilities, including through the provision of sign language interpretation, captioning and Easy-to-Read information?
- How does the EU measure the degree to which extent its measures satisfy the requirements of equal access on equal terms for all? What is the estimated degree of fulfilment of this requirement now?

#### **Article 24: Inclusive education**

Children with disabilities still face difficulties to access European schools of the EU institutions<sup>148</sup> because of discrimination, inaccessibility, and failure to provide reasonable accommodation, as well as the lack of an alternative certification to the European *Baccalaureat*. The exclusion of children with disabilities was highlighted in an EDF's joint report with Human Rights Watch "Sink or Swim": Barriers for Children with Disabilities in the European School System" published in 2018.

Since the 2015 Concluding recommendations and the publication of the joint report, the European Schools reviewed their rejection policy of children with disabilities and still follows a medical approach, where acceptance takes place based on a medical and para-medical assessment.

According to a report published in May 2021, during the 2019-2020 school year, out of a total of 27,841 students<sup>149</sup> 1,379 were receiving intensive support type A<sup>150</sup> and 1 child with special educational needs was refused admission.<sup>151</sup> Because of the lack of inclusive education some parents abstain from enrolling their child with disabilities in the European Schools, quit their job and leave the country. Each year, a number of students with

<sup>&</sup>lt;sup>148</sup> European Schools are intergovernmental schools principally designed for children of employees of EU institutions. The European Schools Board is made up of representatives of the EU Member States and the European Commission.

<sup>&</sup>lt;sup>149</sup> Schola Europaea, <u>Facts and figures on the beginning of the 2018-2019 school year in the European Schools</u> (December 2018).

There are two forms of intensive support. For children with disabilities only type A is relevant. Type B is only short term for students new to the school and having to quickly access a foreign language.

151 Schola Europea, Statistic Report on the Educational Support and on the Integration of Pupils with Special Educational Needs into the European Schools in the Year 2018-2019 (May 2020).

disabilities leave the European Schools and move to another school because of their special educational needs (45 pupils in the school year 2019-2020). The European Schools do not investigate the related reasons. As a majority of staff works and lives in Brussels and surroundings, most pupils are diverted to the Belgian French speaking school system which fails to provide inclusive school system compliant with the CRPD.<sup>152</sup> Staff of EU institutions may also decide to return to their Member States, thus quitting their jobs.

In 2019, the Board of Governors of the European Schools adopted an <u>Action Plan on Educational Support and Inclusive Education</u>. The European Schools are currently in the process of implementing the related actions. Due to the pandemic, many actions have been delayed. While a number of actions led to new policy guidance in various areas of inclusive education, those did not yet translate into concrete improvements of the situation on the ground. A major problem is the lack of monitoring when it comes to implementation at schools' level.

There are also some key actions in the Action Plan, which have not yet been starting, notably those related to the creation of two new education certificates and to the introduction of some flexibility to the curriculum. <sup>153</sup> In addition, the European Schools still lack qualified educational support staff. In the school year 2019-2020, only 21.3% of support teachers had additional qualifications for teaching pupils with special educational needs and only 59.5% of support coordinators had the qualifications required to teach pupils with special educational needs. <sup>154</sup>

The European Schools lack proper mechanisms through which to challenge and to appeal decisions concerning inclusive education.<sup>155</sup>

The <u>Annual plan 2021 of the Office of the Secretary-General of the European Schools</u> envisaged an analysis of the concrete barriers to the curriculum for children with disabilities. It is not clear to which extent this has been carried out.

# Suggested questions:

• What initiative will the EU take to remove the barriers which prevent students with disabilities to enjoy their right to inclusive quality education in the European schools

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<sup>&</sup>lt;sup>152</sup> See UNIA report (2021)

<sup>&</sup>lt;sup>153</sup> European Schools offer a single, highly academic curriculum leading to the European Baccalaureate. There is no other certificate prior to the Baccalaureate cycle (last two school years). The curriculum leading to the European Baccalaureate does not offer any flexibility to adapt to the needs, potential, and learning style of children with disabilities (e.g., students with dyscalculia must pass mathematics in the Baccalaureate). All European Baccalaureate candidates must have followed the full S6 and S7 curriculum to qualify for award of the Baccalaureate diploma.

<sup>&</sup>lt;sup>154</sup> While the European Schools adopted in 2020 some new recommendations regarding the qualifications of support teachers and support coordinators, it remains unclear how those will be applied by schools. The Secretariat General of the European Schools does not foresee a proper monitoring to ensure that in the future all support teachers and support coordinators will have a relevant special qualification in inclusive education.

<sup>&</sup>lt;sup>155</sup> Parents of a child with disabilities can only appeal to the Complaint Board when an application for enrolment or integration is rejected by the Director of a European School. However, there is no proper mechanism to challenge and to appeal other decisions of school directors affecting the education of a child with a disability such as decision to move a child to progression, refusal of applications for reasonable accommodation (related to classroom learning situations or to exams) or of support measures (type or hours of support).

(fully qualified educational support staff, create alternative certificates to the Baccalaureate, introduce flexibility to the curriculum, offer a proper appeal mechanism)?

 Which steps will the EU take to implement a non-rejection policy on the grounds of disability and to prevent that students with disabilities leave the European Schools because of insufficient inclusive, quality education?

#### **Article 25: Health**

The CRPD Committee recommended that the EU revise its health insurance scheme for EU staff members and their relatives, the Joint Sickness Insurance Scheme (JSIS), to provide comprehensive coverage for disability-related health needs. The European Ombudsman, conducted a strategic inquiry on the issue and concluded that the failure of the European Commission to take any effective action in response to the Committee's recommendation amounted to maladministration. She recommended that the Commission revise the rules governing the JSIS and made several suggestions to the Commission relating to how the needs of persons with disabilities are covered under the JSIS, as well as on the need to train staff and properly consult with stakeholders to ensure that the JSIS reflects the needs of persons with disabilities. It was reported to EDF that these recommendations were not adequately addressed by the EU institutions.

In particular, the European Commission's limited revision of the JSIS General Implementing Provisions as regards the implementation of the serious illness criteria in the case of disability was insufficient and did not resolve the underlining problem that the criteria are not suited for assessing disability-related health needs. The EU institutions have yet to establish a comprehensive social protection system, covering both medical and non-medical costs, for staff with disabilities and staff with dependents with disabilities, so as to implement the human rights-based approach.

As regards improvements since the last report of the CRPD, the JSIS set up in 2017 a Centre of Excellence to deal with disability, serious illness and dependence, a single-entry point for staff on health-related disability matters, with an increasing expertise on disability issues. However, it needs more visibility and information to be provided to staff regarding its existence and how it operates.

In relation to the COVID-19 pandemic, there have been gaps in coverage for COVID-19 and its consequences. Despite calls since March 2020, the JSIS did not recognise COVID-19 as a serious illness. Only some health consequences of the virus could be considered serious, on a case-by-case basis. This means that not all costs related to the virus, such as testing and first-line medical care, benefited from full reimbursement. In May, the Office for the Administration and Payment of Individual Entitlements of the European Commission decided that hospitalisation linked to the virus would be reimbursed from the first night on.

#### Suggested questions:

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<sup>&</sup>lt;sup>156</sup> Raised in March 2020 by Union Syndicale Fédérale in <u>The Joint Sickness Insurance Scheme and COVID-19 – time to act</u>

- What steps has the European Commission taken to apply the recommendations of the European Ombudsman?
- When will the JSIS explicitly adopt the concept of disability of the WHO and CPRD
  and set up a framework for the reimbursement of health costs that ensures conditions
  under which persons with disabilities can maintain or improve their health and
  wellbeing, or prevent the deterioration of their health, on an equal basis, and
  according to their health needs and rights?
- How is the JSIS covering the COVID-19 as a serious illness and its potential longterm impact on persons with disabilities?

# **Article 27: Work and employment**

Although the Staff Regulations include a definition of disability that complies with the CRPD, the systems in place for work and employment are not aligned with the CRPD. The system relies too heavily on medical assessments, there are no provisions regarding access to information for employees with disabilities, and recruitment competitions do not include meaningful positive actions for persons with intellectual or psychosocial disabilities.

Some issues related to reasonable accommodations of employees, in particular in the context of the COVID-19 pandemic, is highlighted under **Article 5** above.

There is also a need to establish a comprehensive system for the allowances and entitlements that officials who are carers of persons with disabilities can avail of. All EU institutions follow different procedures, criteria and age thresholds, with different interpretations. This divergence in procedures and practices causes confusion and incomprehension among officials.

It is still unclear precisely how many people working in the EU institutions identify as having a disability, which makes it difficult to monitor their success in achieving an adequate representation of staff with disabilities. The new EU Disability Rights Strategy commits to improving this situation, and to reach out more and have recruitment schemes for persons with disabilities, but at this stage there is little information as to how this will be done and whether it seems likely to create any significant change within the EU institutions. Positive action schemes provide only temporary contracts with a maximum of 6 years, often split in one-year renewable contracts as these contracts are often not supported by the necessary budget. Quotas as foreseen in almost all Member States public administration do not exist nor does the Disability Strategy envisage them.

Carers of persons with disabilities do not receive extra leave for long-term treatment like cures or therapy. Extra support for single parents of children with disabilities is not foreseen.

#### Suggested questions:

- What initiatives has the EU taken to follow up on the CRPD Committee's recommendation to increase the number of employees with disabilities amongst its staff, across all contract categories, including permanent contracts?
- What initiative will the EU take to adopt a formal policy on reasonable accommodation and accessibility, both for the recruitment procedure and to support the performance

- of job functions when the person is hired, including for staff who are carers of persons with disabilities, across all EU jobs, including outsourced and externalised work?
- How will the commitment to facilitate the recruitment of staff with disabilities, as mentioned in the new Disability Rights Strategy, take shape in practice and what will be the indicators used to show if these measures have been successful or not?

# Article 29: Participation in political and public life

The <u>Committee on Petitions</u> of the European Parliament allows citizens and people residing in the EU to submit petition on matters which come within the EU's field of activity and directly affects them. However, the <u>portal to submit petitions</u> is not accessible to Deaf or hard of hearing persons or persons using screen readers.

Another extreme example of exclusion from public life can be found in the flagship democratic exercise of the Conference on the Future of Europe, a joint initiative by the three main EU institutions calling citizens to submit and discuss ideas for the future of the EU through a multilingual digital platform. Unfortunately, persons with disabilities are prevented from participating because the website does not comply with the minimum accessibility requirements adopted in EU legislation concerning Member State's public sector websites and mobile apps. EDF has commissioned an accessibility audit of the Conference platform, and at the time of drafting this report the accessibility issues have not been solved. Additionally, the Conference webstreamed meeting is do not provide sign language interpretation, nor live subtitling, and the documents published are not available in accessible formats.

#### Suggested question:

 What steps will the EU take to ensure that its citizens' initiatives and complaint mechanisms, including the online system to submit petitions to the Commission on Petitions of the European Parliament, are fully accessible to all persons with disabilities?

#### Article 31: Statistics and data collection

The EU institutions do not make public data on candidates who self-identify as persons with disabilities in EPSO competitions, in internal recruitment, or among outsourced staff.

The European Parliament does not conduct any staff surveys, so it does not collect information on disability in any sense, or perceived degree of equal treatment. The Commission has recently conducted a survey focusing on persons who self-identify as persons with disabilities, but the results are not public yet.

#### Suggested question:

 What steps will the EU undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the CRPD within the EU institution and agencies, in procurement and in the European Schools?