



# Disability rights and inclusion in the new EU Global Health Strategy

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# Introduction

There have been major changes in both global health policy and geopolitical landscapes since the European Union (EU) and EU Member States committed to act together on global health in relevant internal and external policies and actions in 2010.<sup>1</sup> There is also more recognition that factors affecting health need to be addressed with a more comprehensive and multisectoral approach to enable the EU to better tackle health inequalities and fight global health threats.

The EU committed to implement the 2030 Agenda for Sustainable Development and its related Sustainable Development Goals (SDGs), which include specific health-related goals and targets as well as the promise to leave no one behind.

Disability inclusion and the rights of persons with disabilities were not addressed by the EU in the 2010 health strategy. However, the EU and all EU Member States have all since ratified the Convention on the Rights of Persons with Disabilities (CRPD)<sup>2</sup>, and have an obligation to adopt all appropriate measures for the implementation of the CRPD, including in relation to health (Article 25) and rehabilitation (Article 26), both within the EU's borders and through its external action, international cooperation, partnerships and humanitarian action (Articles 32 and 11). In 2015, the EU was reviewed by the Committee on the Rights of Persons with Disabilities and presented with recommendations; a second review process for the EU started this year.

We welcome the revision of the EU strategy on global health as an important opportunity to ensure that the new strategy and any related actions are aligned with CRPD obligations as well as with global commitment to leave no one behind in the implementation of the 2030 Agenda, the related SDGs and the more recently adopted World Health Assembly Resolution on the highest attainable standard of health for persons with disabilities<sup>3</sup>.

# Disability inclusion and the right to health

Persons with disabilities account for an estimated 15% of the world's population – roughly one billion people.<sup>4</sup> More than 80% are living in poverty, with an estimated 800 million persons with disabilities living in low- and middle-income countries<sup>5</sup> where disability is more prevalent as poverty and disability often reinforce each other. Persons with disabilities have the same general health requirements as everyone else; at the same time, however, persons with disabilities often have additional specific health needs related to specific impairments or comorbidity, and may require access to specialist health services, such as rehabilitation and assistive devices. Poor physical and social environments can contribute to poor health for persons with disabilities, exacerbating the consequences of impairments and secondary health

<sup>&</sup>lt;sup>1</sup> European Commission, The EU Role in Global Health (2010) <u>https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0128:FIN:EN:PDF</u> <sup>2</sup> Convention on the Rights of Persons with Disabilities (CRPD)

https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

<sup>&</sup>lt;sup>3</sup> WHO Executive Board Resolution EB148.R6, 25 Jan 2021

<sup>&</sup>lt;sup>4</sup> WHO/World Bank World Report on Disability, 2011

<sup>&</sup>lt;sup>5</sup> United Nations Department of Economic and Social Affairs, UN DESA Factsheet on Persons with Disabilities <u>https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html</u>

conditions and leading to co-morbidities. This means that, overall, persons with disabilities have higher requirements for general and specialist health services, compared to the rest of the population.

Yet, persons with disabilities encounter a range of barriers when accessing healthcare including:

- Attitudinal barriers, such as stigma or discrimination by health service providers. For example, health care staff are often not trained to accommodate the fears that persons with disabilities might have around accessing health care treatment and exams.
- Environmental barriers, such as inaccessible buildings or a lack of accessible transport.
- Communication barriers, for example lack of health information in accessible formats.
- Financial barriers due, for example, to higher out-of-pocket health expenses or transport costs and the higher risk of poverty among persons with disabilities.
- Institutional barriers, such as lack of disability inclusion policies in the health sector or, where they exist, policies not being implemented.

Disability inclusion is critical to achieving Universal Health Coverage (UHC). Despite the limited availability of quality data on disability globally, available evidence suggests that persons with disabilities are:

- three times more likely to be denied health care
- four times more likely to be treated badly in the health care system
- 50% more likely to suffer catastrophic health expenditure.<sup>6</sup>

These barriers heighten risks for persons with disabilities posed by the COVID-19 pandemic and other health emergencies. Evidence shows that the one billion persons with disabilities worldwide are among the hardest hit during the COVID-19 pandemic, including in terms of number of fatalities.<sup>7</sup>

Beyond the health sector, persons with disabilities experience further barriers in access to quality food, safe water and sanitation, and housing / shelter which contribute disproportionately to health hazards and poor health outcomes for persons with disabilities, e.g. mobility restrictions and/or lack of accessible transport or inaccessible / poorly targeted social protection systems, or catastrophic health expenditure.<sup>8</sup>

The right to the highest attainable standard of health is a fundamental human right for all which is recognised in international law and human rights treaties. Article 25 of the CRPD addresses health and mandates that State Parties "recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" and "take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation."

<sup>&</sup>lt;sup>6</sup> Kuper, H., & Heydt, P. (2019). The missing billion: access to health services for 1 billion persons with disabilities.

London: London School of Hygiene and Tropical Medicine.

<sup>&</sup>lt;sup>7</sup> UN Policy Brief: a disability-inclusive response to COVID-19 (May 2020)

<sup>&</sup>lt;sup>8</sup> See, for example, <u>Mactaggart et al., 2021</u>

The right to health has also been reaffirmed by a plethora of global commitments such as the 2030 Agenda, and SDG 3 to "ensure healthy lives and promote well-being for all at all ages". In 2019 a United Nations (UN) Political Declaration,<sup>9</sup> endorsed by all UN Member States, recognised the need to increase access to UHC, including for persons with disabilities, and the need to 'remove physical, attitudinal, social, structural, and financial barriers, provide quality standard of care and scale up efforts for their empowerment and inclusion'.

In 2021, the 74th World Health Assembly (WHA) adopted the landmark Resolution WHA74.8 which aims to "make the health sector more inclusive by tackling the significant barriers many persons with disabilities face when they try to access health services." This includes increasing access to health services by breaking down the barriers faced by persons with disabilities; improving protection during health emergencies and inclusion in national response plans; increasing access to public health interventions across different sectors. Resolution WHA71.8 "Improving access to assistive technologies" calls upon UN Member States and WHO to improve effective access to assistive technologies by 2030.

# EU commitments to disability inclusion and inclusive health

In defining and implementing the EU Global Health Strategy, it is pivotal that the EU fully incorporates a disability-inclusive and intersectional approach, in compliance with existing policy frameworks and commitments, and with legal human rights obligations.

Most importantly, the CRPD - ratified by the EU and all its Member States - requires States Parties to adopt all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation (Articles 25 and 26) and to ensure that its international cooperation and humanitarian action are inclusive of persons with disabilities (Articles 11 and 32). The EU must ensure that all EU health initiatives globally are in line with the human rights-based approach to disability and the CRPD.

The Strategy for the Rights of Persons with Disabilities 2021-2030 guides the EU's implementation of the CRPD with the aim to ensure the rights of persons with disabilities, in Europe and beyond, are respected, protected and fulfilled. It includes a specific section on "sustainable and equal access to healthcare" as well as a section on promoting the rights of persons with disabilities globally and supporting their social inclusion "in all international relations, and as part of all external action, policy planning, funding programmes and activities."

In the EU Consensus on Development (2017), the EU and its Member States committed to protect and promote "the right of everyone to enjoy the highest attainable standard of physical and mental health" as well as to support partner countries in "their efforts to build strong, goodquality and resilient health systems, by providing equitable access" to health services and UHC; in the "training, recruitment, deployment and continuous professional development of the health workforce"; and to pursue a 'health in all policies' approach. The EU Consensus places tackling

<sup>&</sup>lt;sup>9</sup> UN High Level Meeting Adopts Historic Declaration on Universal Health Coverage (2019) <u>https://sdg.iisd.org/news/un-high-level-meeting-adopts-historic-declaration-on-universal-health-coverage/</u>

discriminations and inequalities and ensuring an alignment with the 2030 Agenda and SDG principle of leaving no one behind at the heart of EU development cooperation policy, and for the first time includes specific references to persons with disabilities and the CRPD.

We welcome that the EU announced three important commitments<sup>10</sup> on inclusive health at the Global Disability Summit in early 2022, encompassing:

- 1. strengthening health systems including health workforce capacities on disability-inclusive service delivery;
- 2. adding inclusive health, CRPD principles and combatting discrimination as an integral part of its policy dialogue on Universal Health Coverage and Primary Health Care;
- and promoting inclusive health care models and supporting integrated management of non-communicable diseases (NCD), disability and rehabilitation as a key component of the UHC Partnership programme.

The EU also committed to raising the rights of persons with disabilities in dialogues with its partner countries and supporting the implementation of the CRPD.

The EU policy actions, any related programmes, should be coherent, promote and reinforce each other. Therefore, we call on the EU to make sure that the new Global Health Strategy aligns to existing policy commitments and human rights obligations, maximises their impact, and becomes an instrument for implementing the broader, ambitious vision of fighting inequalities, reducing health inequities, and promoting inclusion for all persons with disabilities in society.

# **Recommendations for disability inclusion in priority areas**

1. Accelerate progress in achieving the health-related UN Sustainable Development Goals, in particular Universal Health Coverage (UHC)

**By definition, UHC cannot be universal if it does not include persons with disabilities.** Equity is at the heart of UHC and as such, efforts to advance UHC must focus on reaching the furthest behind first. As governments strive towards UHC as part of Agenda 2030, they need to specifically plan for inclusion in health systems and address the range of barriers affecting access to healthcare for persons with disabilities. Healthcare coverage must be improved, and inclusion must be scaled for all persons with disabilities so that they receive the healthcare they need, when they need it, without incurring financial hardship. Furthermore, disability is rarely included in monitoring frameworks and indicators for UHC – which leads to persons with disabilities becoming invisible within national and local strategies.

Achieving UHC means ensuring that all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient

<sup>&</sup>lt;sup>10</sup> Global Disability Summit 2022, overview of commitments made <u>https://www.globaldisabilitysummit.org/commitments</u>

quality to be effective, while also ensuring that the use of these services does not expose them to financial hardship. Progress towards UHC can therefore be understood across three main dimensions – service coverage, population coverage, and financial coverage. However, persons with disabilities experience barriers and violations of their human rights across these three dimensions.

Persons with disabilities are disproportionately impacted by the limited **availability of quality general and specialist healthcare services**, both in urban and rural areas. Additionally, where services do exist, health facilities, information and communications may not be accessible to persons with different impairments, health personnel may not trained to provide reasonable accommodations for persons with disabilities, and disability data may not be integrated in existing systems.

As part of plans to expand **population coverage**, it is crucial to underscore how persons with disabilities are not a homogeneous group, and some experience more severe discrimination that others. For example, persons with intellectual impairments, persons with mental health conditions and psychosocial disabilities, and deafblind persons tend to experience increased levels of stigma and discrimination across all domains of society, including access to healthcare, compared to persons with other impairments and persons without disabilities. Additionally, persons with disabilities experience complex inequalities related to their intersectional identities. Women and girls with disabilities experience exclusion and discrimination related both to their gender and their disability status. Persons with disabilities who belong to minority ethnic, language, caste, or religious minority groups, those who are migrants, victims of human trafficking, internally displaced people, refugees and asylum seekers or belong to nomadic populations, as well as persons with disabilities belonging to the LGBTQ+ community – all experience multiple layers of discrimination and disproportionate barriers in accessing the healthcare services their require.

Efforts to expand **financial coverage** must take into consideration that persons with disabilities are more likely to live in poverty and often incur higher costs in accessing healthcare. These include both direct expenditures, such as the cost of assistive devices and medications, as well as indirect costs, such as those for accessible transportation. While data is extremely limited, evidence suggest that persons with disabilities tend to access health insurance schemes where these are available – although they may still encounter increased barriers and discrimination compared to the rest of the population (e.g. being excluded on the grounds of pre-existing health conditions), and insurance schemes may not cover specific services required by persons with disabilities, such as rehabilitation and assistive devices.<sup>11</sup>

We call on the EU to fully integrate disability inclusion within strategies aimed at the achievement of the health-related SDGs, and in particular UHC, by:

<sup>&</sup>lt;sup>11</sup> T. Bright, H. Kuper. 2018. A Systematic Review of Access to General Healthcare Services for Persons with disabilities in Low and Middle Income Countries, International Journal of Environmental Research and Public Health 15(09); E2165. Available at: <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6164773/</u>

- Prioritizing disability inclusion as an integral part and a precondition for the achievement of UHC and SDG targets.
- Expanding the provision of healthcare, including goods, information, services, and programmes – including for mental health, rehabilitation, and sexual and reproductive health and rights (SRHR) – that are available, accessible, affordable, acceptable, and of quality for all persons with disabilities in all their diversity, reaching the furthest behind first.
- Establishing inclusive health financing and social protection mechanisms that address the underlying social determinants of health which have a disproportionate negative impact on persons with disabilities and their right to the highest attainable standard of health.
- Supporting governments of EU partner countries to ensure disability inclusive health and care services that are human rights-based, gender responsive, age-sensitive and person-centred – as well as equitable access to cross-sectoral public health interventions, such as safe water, sanitation and hygiene services.
- Supporting the strengthening of Primary Health Care Systems. Community-based, good quality primary healthcare is essential to meet the needs of people adequately who are often left behind due to poverty, gender, disability and the interplay of other discriminating factors.

## 2. Strengthening health systems

#### Governments must increase the amount of domestic resources allocated to health.

Increasing the amount of the national budget allocated to health is considered as central to the attainment and sustainability of UHC. Governments can also consider how they can increase the fiscal space (i.e. amount of available resources in the national budget as a whole) in order to allocate more resources to health. As part of these processes, the inclusion of persons with disabilities needs to be **sufficiently resourced and budgeted for.** Processes should be put in place which allow policy makers to develop budgets which accurately reflect the cost of including persons with disabilities in their work.

Health information and services should go beyond the traditional model and **include promotive**, **preventive**, **curative**, **rehabilitative** and **palliative** health services – as well as **integrated cross-sector Health in All approaches** that **address wider health inequities and social determinants of health affecting persons with disabilities**. These services, including health information, need to be inclusive and accessible to all persons with disabilities in all their diversity.

<u>Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD)</u> recognises that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. The CRPD indicates the following areas for action:

- Accessibility: stop discrimination against persons with disabilities when accessing healthcare, health services, food or fluid, health insurance, and life insurance. This includes making the environment accessible.
- **Affordability:** ensure that persons with disabilities get the same variety, quality, and standard of free and affordable healthcare as other people.
- **Availability**: put early intervention and treatment services as close as possible to where people live in their communities.
- **Quality**: ensure that health workers give the same quality care to people with disabilities as to others.

Despite the existence of these legal obligations, persons with disabilities face several barriers in attaining the highest attainable standard of health. The EU has failed to adopt strong and effective actions to **protect persons with disabilities against discrimination in access to healthcare.** Under EU law, persons with disabilities are only protected against discrimination in the field of employment and vocational training. 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 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.

Persons with disabilities are often **discriminated against by health workers and other professionals** on the basis of their disability. In this way, they do not receive the same quality of healthcare as others.

**Rehabilitation** is crucial to effectively respond to current health trends (ageing, increased prevalence of non-communicable diseases, frequent health emergencies) and is an important part of the right to health for persons with disabilities and their participation in society<sup>12</sup>. However, rehabilitation services are often under-developed and under-resourced; while an estimated 2.4 billion people globally need access to rehabilitation services, more than 50% do not have access to them. In some low- and middle-income countries, only 3-5% of persons with disabilities are able to access rehabilitation services. Additionally, persons with disabilities lack **assistive technologies**. It is estimated that 1 in 3 people, or more than 2.5 billion, globally need at least one assistive product, but access to assistive technology ranges from 90% to as low as 3%, showing huge disparities and that needs are severely unmet in many parts of the world<sup>13</sup>. Lack of provision of assistive technology exacerbates other barriers to accessing health services for persons with disabilities.

Article 23 of the CRPD prohibits discrimination against persons with disabilities in all matters relating to marriage, family, parenthood, and relationships, affirming that persons with disabilities have the right to make free and informed decisions about their sexual and

 <sup>&</sup>lt;sup>12</sup> See also, Making the case for rehabilitation in the new EU Global Health Strategy, 2022
<u>https://wfot.org/assets/resources/Making-the-case-for-rehabilitation-in-the-new-EU-Global-Health-Strategy.pdf</u>
<sup>13</sup> WHO and UNICEF, 2022, Global Report on Assistive Technology (GReAT) <u>https://www.who.int/teams/health-product-policy-and-standards/assistive-and-medical-technology/assistive-technology/global-report-on-assistive-technology</u>

reproductive health, including the timing and spacing of their children, and the right to access age-appropriate information, and reproductive and family planning education and services. Nevertheless, the **sexual and reproductive health and rights** of persons with disabilities – particularly adolescent girls and young women with disabilities – are not sufficiently taken into account by governments. Persons with disabilities often struggle to access treatment for their primary conditions, but experience even more barriers in accessing sexual and reproductive health and rights services and information – especially on contraception, abortion, sexual education – which leads to a lack of prevention, in particular gynaecological smears and mammography. Stigma, discrimination and negative assumptions leave **women and girls with disabilities more vulnerable to abuse, unwanted pregnancies, sexually transmitted infections** and other risks. **Women in institutions** are poorly included in prevention policies. Furthermore, girls and women with disabilities are at a higher risk of being subjected to **forced contraception, sterilisation and abortion**. Yet, the EU 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.

**Persons with mental health conditions and psychosocial disabilities** continue to experience severe violations of their freedoms and rights, and large numbers of persons with disabilities around the world continue experiencing **institutionalization**. The COVID-19 pandemic has exacerbated the already existing inequalities and exposed horrific human rights violations in institutional care settings. It has brought to fore **the need to accelerate deinstitutionalisation and promote community-based support services**.

The majority of health and care systems worldwide remain unprepared for the demographic and epidemiological transition all countries are experiencing. Progress towards achieving UHC presents an opportunity to reorient health and care systems to support healthy ageing and to meet the needs and uphold the rights of **increasing numbers of older people and persons with disabilities with a higher prevalence of chronic and complex conditions**. There is a strong interplay between non-communicable diseases (NCDs), disability and older age. NCDs are the leading cause of disability and death globally, and persons with disabilities and older people are more at risk from NCDs due to underlying health conditions and unmet health needs, greater levels of poverty and exclusion from services. Insufficient attention has been given to disability and ageing in global NCD policies. The EU Global Health Strategy provides an important opportunity to address this gap.

#### For all these reasons, we call on the EU to:

- Strengthen inclusive health systems that provide access to general health care and specialised services and programmes related to disability-specific health requirements, across the spectrum of care and throughout the life course by:
  - Mainstreaming disability inclusion across all health care services and programmes, including primary care, rehabilitation and assistive technologies, comprehensive sexual and reproductive health services, and mental health services, and by providing access to specialist services and programmes related to disability-specific health requirements. Persons with disabilities should not be asked to wait for a

disproportionate length of time to access these specialist services, and in some circumstances should be given priority.

- Making all services available in the community, with health service delivery models that promote multi-sectoral collaboration and action, as well as independent living in the community, accelerating deinstitutionalization of persons with disabilities from all types of institutions, with respect for the autonomy of all persons with disabilities and their right to engage in their own health and well-being, and the right to legal capacity to do so.
- Protecting women and girls with disabilities against violence and abuse, and the maintenance of accessible support services, including those regarding their sexual and reproductive health and rights in the implementation of the EUs Gender Action Plan III and its activities in response of COVID-19. Governments and service providers should provide disability-, gender- and age-inclusive sexual and reproductive services, in particular for adolescent girls who experience barriers to accessing information and/or marginalisation from education.

#### Review legal frameworks to promote inclusive health

- By recognising by law the right of persons with disabilities to the highest attainable standard of health and removing all legal barriers that prevent them from accessing health and health care-related information, goods, services, and programmes including EU and national legislation that discriminates against them in the provision of health insurance, and in the recognition of legal capacity, establishing regulatory and accountability mechanisms to ensure the rights of all persons with disabilities are respected, protected, and fulfilled.
- Mobilise resources to guarantee the right to enjoy the highest attainable standard of health for persons with disabilities
  - By providing dedicated funding to disability-specific programmes aimed at promoting good health and wellbeing outcomes for persons with disabilities through equitable access to preventative, promotive, curative, rehabilitative and palliative care and assistive technologies, and by dedicating resources for disability inclusion in mainstream health programmes and social protection mechanisms.
  - By promoting the availability and affordability of medicines and devices to all particularly considering that persons with disabilities are already far more likely to have low incomes and high outgoings.<sup>14</sup>
- Build capacities on disability inclusive health in the health workforce and in service delivery
  - By supporting its partner countries to develop a health workforce that has the understanding, competence, knowledge, skills and attitudes to address the health requirements of persons with disabilities in all their diversity, including showing

<sup>&</sup>lt;sup>14</sup> European Disability Fund (EDF), 2021, Human Rights Report 2021: Impact of COVID19 on persons with disabilities, <u>https://www.edf-feph.org/publications/human-rights-report-2021-impact-of-covid19-on-persons-with-disabilities/</u>

patience and reasonable accommodation for patients who might have fear around the given healthcare treatment, and in reviewing health workforce curricula to enhance a human-rights based and intersectional approach to disability, including persons with psychosocial and intellectual disabilities, to address stigma, stereotyping, and discrimination in health service delivery.

- Address multiple and intersecting discrimination in the health sector
  - By designing and funding health programmes designed to address the multiple and intersecting forms of discrimination experienced by persons with disabilities in all their diversity, and particularly women and girls with disabilities, by ensuring the full realisation of their right to sexual and reproductive health, respecting bodily autonomy and informed consent, and strengthen efforts to address barriers faced by persons with disabilities based on their intersectionality identities, including those belonging to marginalised or vulnerable populations, ensuring there are targeted measures to eliminate discrimination.
- Incorporate a mental health approach in line with the principles of the CRPD
  - Incorporate a disability inclusive, human rights-based and person-centred approach to mental health into health programmes and health benefit plans as a population approach to mental health with a life-course perspective; further establish multisectoral collaboration to act on social and underlying determinants of mental health, reach traditionally underserved populations in accessible and respectful ways, and deinstitutionalise care, building competencies across non-specialised health services and promoting continuity of care in community settings, with support and supervision through a wide network, including from mental health specialists.
- 3. Improve pandemic prevention, preparedness and response

**Disability inclusion and participation in health must be ensured in health emergencies, humanitarian contexts and disaster preparedness planning.** Evidence gathered from previous disasters and emergencies shows that persons with disabilities are disproportionately affected and experience higher rates of mortality and morbidity.

The EU largely failed to include persons with disabilities in their response to the COVID-19 pandemic, both within Europe and in their global response. This failure increased the barriers faced by persons with disabilities in accessing health care, education, work, to be free from violence, abuse and neglect and to live independently in the community. COVID-19 further compounded the social exclusion and poverty in which many persons with disabilities live and exacerbated stark health inequities already experienced by persons with disabilities.

Persons with disabilities belonging to other disadvantaged groups were even more marginalised during the crisis and put at greater risk of COVID-19 infection and impact. For example, persons with intellectual or psychosocial disabilities, were more likely to be excluded from services or be

forced to live in institutions which have been shown to be an environment where the COVID-19 virus is exacerbated.<sup>15</sup>

The disability movement at the international level<sup>16</sup> documented some of the key barriers that persons with disabilities faced during the pandemic:

- Alarming number of deaths in institutions and other closed settings<sup>17</sup>
- Gaps in continuity of health care, medical treatment and support services: During the pandemic peak and lockdown, continuity of health services, care and medical treatment could not be ensured due to constrained resources and years of reduced budgets allocated to the health and social sector. Often, these services are important and lifesaving, such as rehabilitation services and medicine for people with epilepsy.
- Inaccessible information, communication, transport and building: although some governments started to provide public health announcements in accessible formats, this came too late and was not consistent. Persons with disabilities lacked the essential information related to the pandemic on how to keep themselves safe. Persons with disabilities were denied their right to make informed decisions, for example due to the lack of sign language interpreters. Transport and physical buildings (including health facilities, and testing and quarantine centres) are often inaccessible.
- **Domestic and sexual violence**: Data shows that since the start of the COVID-19 pandemic, and especially during lockdown measures, violence against women and domestic violence has intensified. The UN Office of the High Commissioner for Human Rights (OHCHR) has reported that, globally, women with disabilities, although likely facing higher numbers of domestic violence, are reporting less.
- **Denial of access to healthcare**: Because of inaccessibility and discrimination, persons with disabilities have greater difficulties in accessing healthcare and life-saving interventions, including in times of pandemic. In some countries, persons with disabilities are directly discriminated against through triage protocols or indirectly discriminated against due to de-prioritisation.<sup>18</sup>

Marginalisation and poor health outcomes for persons with disabilities witnessed during COVID-19, the Ebola, and other public health emergencies over recent years has underlined the importance of ensuring active and effective measures to include persons with disabilities and

<sup>&</sup>lt;sup>15</sup> EDF position paper 'EUs global role in the COVID 19 response and impact on lives of persons with disabilities' (2021)

<sup>&</sup>lt;sup>16</sup> <u>COVID-19 Disability Rights Monitor Report</u>, COVID-19 Disability Rights Monitor (October 2020): The report is the result of a major global initiative aimed at conducting rapid, independent monitoring of state measures to assess the impact of COVID-19 on persons with disabilities. International Disability Alliance, <u>End Discrimination Campaign</u>, <u>COVID-19</u>

<sup>&</sup>lt;sup>17</sup> United Nations, <u>Policy Brief: The Impact of COVID-19 on older persons</u>, (May 2020)

<sup>&</sup>lt;sup>18</sup> United Nations, Policy Brief: a disability-inclusive response to COVID-19 (May 2020)

https://unsdg.un.org/sites/default/files/2020-05/Policy-Brief-A-Disability-Inclusive-Response-to-COVID-19.pdf

enable their participation in emergencies preparedness and response – particularly building on lessons learnt in recent years<sup>19</sup>.

Article 11 of the CRPD calls upon States Parties to take 'all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk'. There is an urgent need to invest in disability-inclusive health emergency preparedness, response and recovery.

#### We call on the EU to:

- Ensure that it makes health equity and the inclusion of persons with disabilities an integral part of health emergency preparedness and response:
  - The EU Global Health Strategy should place emphasis on equity as a principle, objective, indicator and outcome of health emergency preparedness and response (HEPR). It is essential that equity in HEPR includes action to address health inequities and to realize the right to the highest attainable standard of health for persons with disabilities. The strategy should emphasise a rights-based approach in all aspects of HEPR, including protections against discrimination.
  - UHC and health system strengthening (HSS) are essential for effective pandemic prevention, preparedness and response globally. The Global Health Strategy should actively promote health system strengthening as a core aspect of HEPR with an emphasis on ensuring available, accessible, acceptable and quality health care for those further behind, including persons with disabilities, through a primary health care approach and action to address the underlying determinants of health.
  - By mainstreaming disability inclusion in emergency preparedness and response plans throughout all stages of the global EU humanitarian programme cycle, including in Team Europe's work. This strategy should be 'twin-track', with targeted actions to support persons with disabilities and inclusive and accessible mainstream services. It will, for example, include the obligation for fully accessible public health announcements, emergency communication, as well as initiatives around employment and social protection.
  - By providing access to health care services for persons with disabilities during and post-health emergencies, with particular emphasis on safe water, sanitation and hygiene services, fundamental access to sexual and reproductive health services and gender-based violence response services, recognising the particular vulnerabilities of persons with disabilities and their families in health emergencies.
  - Protecting the right to life to all persons, including persons with disabilities, must be a core objective of the EU Global Health Strategy, from prevention and preparedness, testing, treatment and vaccination. Part of foreseeing responses to future health crises will therefore require ensuring that the response is adapted to the needs of persons with disabilities. This means ensuring that medicines and devices developed in response to a health crisis can be used by all, and that particularly high-risk groups should be prioritised in the distribution of vaccines.

<sup>&</sup>lt;sup>19</sup> International Disability and Development Consortium (IDDC), 2021. Adjust and Respond - The experience of organisations working with people with disabilities in adapting to the COVID-19 pandemic: <u>https://www.iddcconsortium.net/wp-content/uploads/2021/06/IDDC-Adjust-and-Respond\_web.pdf</u>

- By strengthening disability inclusion across health systems and the continuum of care, including through the collection, analysis and use of data disaggregated by disability.
- By ensuring access to inclusive public health information, risk communication and participatory community mobilisation measures. This includes providing emergency information through public broadcasting, but also via written or other means in dedicated websites, mobile apps and digital platforms. The EU Global Health Strategy should be consistent with EU policies and legislation to ensure persons with disabilities have equal access to technologies and information required during public health emergencies. Digitalisation process should ensure that development of new technologies to tackle public health emergencies are accessible for persons with disabilities.
- By ensuring that essential services and support, including rehabilitation, psychosocial support and interpreting services, are adapted and continue to operate and be accessible to all persons with disabilities.

## 4. Apply the 'One Health' approach comprehensively

A One Health approach is key to tackle the environmental-health nexus and the diverse experiences of its co-benefits and negative externalities.

Through systemic thinking, the One Health vision considers syndemic where many factors, like barriers to health information and services faced by persons with disabilities, may adversely interact exacerbating health inequities. For instance, the recent pandemic of SARS-CoV2, a zoonosis, disproportionately affected persons with disabilities. Research has also shown that persons with disabilities are being systematically ignored when it comes to the climate crisis, even though they are particularly at risk from the impacts of extreme weather. Persons with disabilities are more likely to experience challenges in the environmental determinants of health (like exposure to indoor air pollution and chemicals) and social determinants of health (like housing, energy poverty, and food systems) with negative impact on health outcomes and quality of life.

#### We call on the EU to:

- Ensure meaningful participation in Disaster Risk Reduction preparedness and planning, inclusive response to health emergencies, accessible information and capacity-building on the emergent field of One Health, and accessible climate resilient and environmentally sustainable health care facilities.
- Create One Health interventions and solutions (both nature-based and technology innovation) which are inclusive and supporting environments for all.

## **Recommendations for an Inclusive Strategy**

## 5. Participatory approach and governance

Persons with disabilities through their representative organisations are not sufficiently involved and consulted in the EU global health policy processes, including in the EU COVID-19 response and recovery plans – despite this being an obligation under Article 4.3 of the CRPD.

All EU health initiatives globally fail to adopt an intersectional approach, which recognises specific and additional barriers faced by women and girls with disabilities, children with disabilities and older persons with disabilities, among others. Such disability inclusive and intersectional approach is required in all phases of funding, from programming and implementation, to monitoring and evaluation – with a view to ensuring that those at most risk are reached first and that all interventions respond to the specific needs of different groups. Intersectionality is also important when involving persons with disabilities and their representative organisations.

## We call on the EU to:

- Engage civil society, in particular organisations of persons with disabilities (OPDs), in health-related policy design, planning, implementation, monitoring and evaluation:
  - By ensuring that the EU Annual Global Health Policy Forum and any other stakeholders' consultation related to the EU Global Health Strategy are fully accessible and inclusive of all persons with disabilities.
  - By actively engaging persons with disabilities and their representative organisations, purposefully including organisations of women and youth with disabilities and underrepresented OPDs such as those representing persons with psychosocial disabilities or deaf-blindness, in decision-making processes in the health sector and in collaboration with health experts, to support in the design, planning, implementation, monitoring and evaluation of health strategies, policies, legislation, public health interventions, health service design and provision, research, and financing to ensure that they are fully inclusive of persons with disabilities, as well as implement integrated national programmes on assistive technology based on data and consultations with OPDs and users of assistive technologies.
  - By building the capacity and ensuring funding civil society, and in particular for representative organisations of persons with disabilities globally as to ensure their equal participation in policy design, planning, implementation, monitoring and evaluation.

## 6. Implementation and funding

The 140 EU delegations in partners countries often fail to be accessible to persons with disabilities, and do not systematically include civil society, including OPDs and community-based organisations, in local and regional political, policy and human rights dialogues with the governments of partner countries, including those related to health sector policies and programming.

#### We call on the EU to:

- Ensure that all EU delegations are inclusive of and accessible to all persons with disabilities and include civil society and in particular OPDs in its dialogues with governments of partner countries.
- Train staff of the EU delegations on disability issues, the CRPD and the needs of persons with disabilities, including women and girls with disabilities, in the areas of international cooperation, emergency response and humanitarian aid.
- Ensure that across all sectors, all EU funded actions, external investments and donorfunded actions uphold the principles of accessibility, dignity, and the inclusion in the community of the most marginalised groups, including persons with disabilities. No funds should be invested externally in creating or exacerbating barriers or segregation of institutionalisation for persons with disabilities.<sup>20</sup>

## 7. Evidence and data

The lack of quality data on the inclusion of persons with disabilities in all aspects of society, including healthcare, is a major gap at global level, which leads to persons with disabilities being systematically excluded from global decisions about development investments, humanitarian responses and poverty alleviation strategies<sup>21</sup>.

It is crucial to **integrate disability data and statistics within censuses, population-based surveys and routine data collection processes** in the health sector, using tools which are based on a human rights approach to disability and meet international standards of comparability, such as the Washington Group Questions on Disability Statistics<sup>22</sup>.

The collection and use of disaggregated data through Health Management Information Systems (HMIS) should be strengthened. Data that can be disaggregated by, for example, gender, age, disability status etc, should be collected from health centres and utilised to inform where services are needed, what services are needed and what policies need to address. It is essential that good quality data on disability status is collected through HMIS. Consideration should be given to improving the interoperability of health data to support targeted social protection to reduce financial health risks for persons with disabilities. Currently, data are not disaggregated, or when they are, data of persons with disabilities living in closed settings such as institutions are not collected.

Investment in disaggregated data on disability type, age and gender is also needed to advance knowledge on how inclusive EU funds in health are. The Organisation for Economic Cooperation and Development (OECD) Development Assistance Committee (DAC) disability

content/uploads/2021/05/The-Disability-Data-Report-2021.pdf

 <sup>&</sup>lt;sup>20</sup> Bridging the Gap-II, call to action on disability inclusive development (2021) <u>https://bridgingthegap-project.eu/wp-content/uploads/2021/09/Infographic-Inclusive-Development-Cooperation-EN-1.pdf</u>
<sup>21</sup> Mitra, S. and Yap, J. (2021). The Disability Data Report. Disability Data Initiative. Fordham Research Consortium on Disability: New York. <u>https://disabilitydata.ace.fordham.edu/wp-</u>

<sup>&</sup>lt;sup>22</sup> <u>https://www.washingtongroup-disability.com/</u>

**inclusion marker** should be enforced in all EU global health policies and programmes, to monitor finance in support of persons with disabilities.

#### We call on the EU to:

- Optimise the use of data on disability inclusion to inform health policies and investments
  - By strengthening health information systems to collect and analyse data on health inequities to inform the design of disability inclusive health policies and investments, including statistical and research data disaggregated by gender, age and disability, and on the health status and access to health care of persons with disabilities.
  - By systematically collecting disaggregated and globally comparable data and using the data for evidence-based policy making and inclusive programming. Data should be disaggregated by at least gender, age and disability and aligned with the domestic SDG reporting on the respective targets.
  - By supporting its partner countries to disaggregate data and strengthen their health management information systems.
- Implement the OECD DAC disability policy marker to track development finance in support of persons with disabilities, including for health finance and investments.

## 8. Role of EU in the global health architecture

Given the position of the EU as the only regional body to have signed and ratified the CRPD, as one of the largest donors of overseas development assistance (ODA), and as a key trade partner, the EU must lead by example in its implementation of the CRPD, including in relation to inclusive health. The EU should champion the rights of persons with disabilities, both within the EU and through its external action policies and programmes, including those related to global health.

EDF and IDDC have previously called for the EU to adopt an EU Disability Action Plan to ensure the rights of persons with disabilities are promoted and respected across all of its external action policies and programmes, including in global health and humanitarian emergencies such as the COVID-19 crisis. This should include supporting partners on the implementation of the CRPD and on health systems strengthening and achieving UHC – which the EU has already committed to do in the EU Action Plan on Human Rights and Democracy 2021-2024.

"Team Europe" contributed €500 million to COVAX to provide one billion COVID-19 vaccines doses in December 2020. The countries the most in need to receive support from COVAX are 92 countries that cannot afford to buy vaccines on their own. They are also countries where often persons with disabilities are viewed as second-class citizens and where their rights are systematically denied and violated. The new suggested EU mechanism by the Commission President, Ursula von der Leyen where member countries could donate doses to the global south should ensure the prioritization of persons with disabilities.

#### We call on the EU to:

- Champion the rights of persons with disabilities in its multilateral, bilateral and regional cooperation and partnerships, and to ensure better coordination and joint approaches to act on commitments already made at the global and regional levels.
- Actively engage in the Global Action on Disability (GLAD) Network, including its working group on inclusive health, which provides a platform to exchange good practices on how to ensure better disability inclusion in the health sector and in health emergencies. And in addition to encourage its Member States to actively engage in GLAD.
- Through effective international partnerships with GAVI and the WHO for instance, ensure equitable access to testing, treatment and vaccination for persons with disabilities in countries with less robust healthcare systems and economies. The EU must advocate for the COVAX initiative to prioritise persons with disabilities and speedup the delivery of vaccine delivery in the world.

# About us

**European Disability Forum (EDF):** <u>EDF</u> is an umbrella organisation of persons with disabilities that defends the interests of Europeans with disabilities. EDF is a strong, united voice of persons with disabilities in Europe. EDF also plays an active role in ensuring persons with disabilities and their representative organisations are included in EU external action.

**International Disability and Development Consortium (IDDC)**: <u>IDDC</u> is a global consortium of disability and development non-governmental organisations (NGOs), mainstream development NGOs and representative OPDs supporting disability and development work in more than 150 countries around the world. The aim of IDDC is to promote rights-based disability inclusive development and humanitarian action.