

## COFACE Response to the European Commission's Public consultation on the preparation of a new EU Disability Strategy 2010-2020

4 January 2010

### **Foreword**

This paper aims at completing COFACE's response to the European Commission's questionnaire, submitted online (see Annex).

COFACE welcomes the opportunity to contribute to the preparation of the new EU Disability Strategy. However COFACE deeply regrets that an online, multiple choice questionnaire, available mostly in English, and with very little space allocated for additional comments, has been the method chosen for this consultation. It considerably limits the range of the consultation (issue of languages and of accessibility) as well as the quality of input.

Hence, COFACE wishes to submit this additional paper, and sincerely hopes that it will receive due and careful consideration. COFACE is eager to contribute to the next steps of the development of the strategy and remains at the disposal of the European Commission Unit for the Integration of Persons with Disabilities.

### **Support to a European Disability Pact!**

COFACE broadly supports the [proposal from the European Disability Forum \(EDF\) for a European Pact on Equal Rights of Persons with disabilities](#) , including its priorities.

This pact would create the suitable framework for European policies aimed at promoting the rights of persons with disabilities and to give impetus to the coordination of disability policies among EU Member States and the EU institutions. It would give a clear long term direction to disability policy at European level.

## Acknowledgement of the family dimension of disability and of disability policies

The Preamble of the UN Convention on the Rights of Persons with Disabilities states that '*persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities*'. This statement feeds into many of the subsequent articles of the Convention.

Disability indeed has a clear family dimension, where families are the primary responsible for the education of children with disabilities, and where families are often one of the best support contexts in which persons with disabilities with complex dependency needs are able to fulfil their lives. Finally, persons with disabilities often face obstacles when exercising their own right to found a family.

This should be reflected in EU related policies through:

- a clear acknowledgement in the new strategy of the need for an **holistic support to families of persons with disabilities**, going beyond the sole question of independent living;
- **mainstreaming** of this issue in relevant policies.
  - e.g.
    - Education: inclusive education policies should encompass a number of measures directed at parents (information, awareness raising, and empowerment; involvement in the design, implementation and evaluation and of the individual educational plan; ...);
    - Independent living: transition from institutional to community-based care should encompass the development of quality family support services, ranging from information and training to respite services;
    - Standards of living and social protection: families of persons with disabilities (including of children with disabilities) face a higher risk of poverty. Social protection systems must be improved also in their favour, including through measures for reconciling family life and professional life, pension and social security rights, etc;
    - Freedom of movement: in order for persons with disabilities and their families (and in particular families with children with disabilities) to enjoy the right to free movement, harmonisation/coordination must not only concern measures directed at persons with disabilities but also those directed at their families (e.g. work/life balance measures);
    - Access to goods and services, transport and built environment: household with a person with disability should for instance be ensured access to accessible housing, without discrimination and extra-cost;
    - Culture, recreation, leisure and sport: for instance, access to holidays for persons with disabilities and their families should be facilitated through accessible holiday amenities and financial support compensating for the extra-cost;
    - Freedom and dignity: prevention of psychological and physical exhaustion of family carers are key to prevent neglect and abuse, while when family members are chosen as support person by a person with disability in the exercise of his/her legal capacity, these relatives should be helped;
    - etc.

Such mainstreaming requires a **stronger cooperation and coordination** on this issue of the European Commission Unit for the Integration of Persons with Disabilities a number of Commission services

(and in particular: services responsible for social protection, social inclusion, gender equality, and demographic issues).

This also pleads for a **continuous involvement of organisations representing families of persons with disabilities** in the discussion at EU level. If the Committee on Disability proposed by EDF is to be established, mechanisms should be found to ensure that family organisations are involved at least to the same extent as is currently the case with the EU Disability High Level Group (where COFACE has a seat).

### **Do not forget the most vulnerable!**

People with severe disabilities and/or complex needs are one of the most excluded groups of citizen in the European Union, because of values and general market dynamics of modern European societies, of the perception of a person with severe disabilities or complex needs as not being capable to take over a socially accepted mainstream role in life, and because of prejudices and negative attitudes against these persons and their families<sup>1</sup>.

It is therefore crucial that the new strategy puts a special focus on the integration of persons with severe disabilities and/or complex needs, through the mainstreaming of this issue and a tailored approach when needed.

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<sup>1</sup> Findings from the European Study [‘The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs’](#)

**For further information:**

COFACE positions on disability-related issues:

- COFACE-Handicap [European Charter for Family Carers](#)
- COFACE position on [siblings and persons with care needs](#)

COFACE positions on family and social policies issues, with disability relevance:

- COFACE position on [reconciling family life, private life and professional life to prevent poverty and social exclusion](#)
- COFACE recommendations on [active inclusion, a tool for fighting family poverty](#)
- COFACE position on [the role of personal income taxation in preventing family poverty](#)

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EUROPEAN COMMISSION  
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<http://ec.europa.eu/social/main.jsp?catId=327&langId=en>

## **Annex: COFACE's response to the European Commission's online questionnaire**

<b>GENERAL INFORMATION</b>	
Are you replying:	On behalf of an organisation
What type of organisation do you represent?	Non-governmental organisation, including disability NGO
What is the name of your organisation?	Confederation of Family Organisations in the European Union (COFACE)
What is your <b>Interest Representative Register</b> ID, if applicable?	09583441226-34
Please give the contact e-mail address of your organisation	secretariat@coface-eu.org
<b>1. WHAT SHOULD THE NEW EU DISABILITY STRATEGY COVER?</b>	
<b>1.1 Please indicate how strongly you agree or disagree with the following statements.</b>	
Persons with disabilities can participate in everyday activities as fully as other citizens	strongly disagree
Persons with disabilities enjoy the same rights as other citizens	strongly disagree
Persons with disabilities face discrimination in their everyday activities because of their disabilities	strongly agree
EU citizens with disabilities find it more difficult to move to another Member State than other EU citizens	strongly agree
<b>1.2 How important are the following problems for persons with disabilities?</b>	
Lack of access to built environment	very important
Lack of access to transport	very important
Lack of access to Internet and communication technologies	very important
Lack of access to other customised goods and services	very important
Lack of equal opportunities in the labour market	very important
Lack of equal opportunities in education	very important
Lack of equal access to healthcare (doctors, hospitals etc.)	very important
Barriers to free movement within the EU	very important

Difficulty in living independently (for instance institutionalisation, lack of services in the community)	very important
Difficulty of participating in democratic and public life	very important
Difficulty of participating in cultural life, recreation, leisure and sport	very important
Poverty and low income	very important
Mistreatment (such as abuse or neglect of liberty and dignity)	very important
1.3 Have you personally experienced any of the problems mentioned in Question 1.2?	Only indirectly, through the experience of persons close to me, such as family or friends
<b>2.1 Thematic areas: ACCESSIBILITY</b>	
<b>2.1.1 How effective are the following measures in improving <u>accessibility</u> for the persons with disabilities?</b>	
<b>Developing guidelines and standards to promote accessibility of:</b> (1) the built environment	effective
(2) transport	effective
(3) Internet and communication technologies	effective
(4) other goods and services	effective
<b>Developing legislation to ensure accessibility of:</b> (1) the built environment	very effective
(2) transport	very effective
(3) Internet and communication technologies	very effective
(4) other goods and services	very effective
<b>Funding for research on accessibility of:</b> (1) the built environment	somewhat effective
(2) transport	somewhat effective
(3) Internet and communication technologies	somewhat effective
(4) other goods and services	somewhat effective
<b>Measuring accessibility of:</b> (1) the built environment	somewhat effective
(2) transport	somewhat effective
(3) Internet and communication technologies	somewhat effective
(4) other goods and services	somewhat effective
Providing know-how to support application of the "reasonable accommodation" principle	effective

Greater involvement of persons with disabilities in developing accessibility standards	effective
Increasing use of "universal design" or "design for all"	very effective
Regular checks of accessibility of goods and services	effective
Increasing availability of assistive technologies	effective
Supporting the development of the assistive devices industry	effective
<b>2.1.2 Compared to now, how much should the following contribute to improving <u>accessibility</u> for persons with disabilities?</b>	
European Union	more
National government	much more
Regional/local government	much more
NGOs, including disability NGOs	more
Private sector	much more
Other	
2.1.3 If you choose "Other", please specify:	
<b>2.2 Thematic areas: EMPLOYMENT</b>	
<b>2.2.1 How useful are the following to persons with disabilities in seeking <u>employment</u>:</b>	
Providing training to job-seekers with disabilities	very useful
More and better labour market support services	very useful
Raising awareness of the potential of persons with disabilities among employers	useful
Promoting opportunities for self-employment	useful
Increasing accessibility of workplaces	very useful
Providing assistive technologies	very useful
Better accessibility of standard technologies and digital content	useful
Fighting discrimination related to recruitment, employment and career advancement	very useful
Enforcing the obligation to make reasonable accommodation for disabled persons at the workplace	very useful
Reducing financial risks for persons with	very useful

disabilities entering or leaving the labour market	
<b>2.2.2 Compared to now, how much should the following contribute to increasing employment of persons with disabilities?</b>	
European Union	more
National government	much more
Regional/local government	much more
NGOs, including disability NGOs	more
Private sector	much more
Other	much more
2.2.3 If you choose "Other", please specify Social partners	
<b>2.3 Thematic areas: EDUCATION</b>	
<b>2.3.1 How much will the following improve equal opportunities for persons with disabilities in <u>education</u> and training?</b>	
Increasing human and financial resources to bring students with disabilities into the general and higher education system	very much
Facilitating mechanisms for students with disabilities to move from special to general education	very much
Providing specific training for teachers to accommodate students with disabilities in their classrooms	very much
Providing scholarships and grants for persons with disabilities	somewhat
Increasing the availability of accessible learning material, including electronic material and assistive technologies	very much
Increasing the accessibility of educational buildings	very much
Awareness-raising activities in the general education system to increase social acceptance and understanding of the needs of persons with disabilities	very much
Adapting adult education and training programmes to the needs of persons with disabilities	very much
<b>2.3.2 Compared to now, how much should the following contribute to ensuring persons with disabilities in <u>education</u> enjoy equal opportunities?</b>	
European Union	much more

National government	much more
Regional/local government	much more
NGOs, including disability NGOs	more
Private sector	more
Other	much more
2.3.3 If you choose "Other", please specify Schools and school staff should also be more proactive in contributing to equal opportunities	
<b>2.4 Thematic areas: HEALTHCARE</b>	
<b>2.4.1 How much will the following improve equal access to <u>healthcare</u> for persons with disabilities?</b>	
Providing training for health professionals on health needs of persons with disabilities	very much
Developing more health services for special needs of persons with disabilities	clearly
Preventive action to reduce the incidence of disabilities	very much
Prohibiting discrimination against persons with disabilities in the provision of health insurance	very much
<b>2.4.2 Compared to now, how much should the following contribute to ensuring persons with disabilities enjoy equal access to <u>healthcare</u>?</b>	
European Union	much more
National government	much more
Regional/local government	much more
NGOs, including disability NGOs	same
Private sector	much more
Other	
2.4.3 If you choose "Other", please specify	
<b>2.5 Thematic areas: FREE MOVEMENT</b>	
<b>2.5.1 To what degree will the following help to ensure persons with disabilities enjoy the right to <u>free movement</u>?</b>	
Portability of disability-related benefits and services when moving to another Member State	very much
Mutual recognition of disability status across the Member States	very much
Harmonisation of criteria used by the Member States to assess the degree of disability	clearly

Work towards similar disability related benefits across the Member States	clearly
<b>2.5.2 Compared to now, how much should the following contribute to ensuring persons with disabilities enjoy the right to <u>free movement</u>?</b>	
European Union	much more
National government	much more
Regional/local government	more
NGOs, including disability NGOs	more
Private sector	more
Other	
2.5.3 If you choose "Other", please specify	
<b>2.6 Thematic areas: INDEPENDENT LIVING</b>	
<b>2.6.1 How much will the following increase the ability of the persons with disabilities to <u>live independently</u>?</b>	
Avoiding the placement of persons with disabilities in residential institutions by: (1) supporting families and other informal carers	very much
(2) increasing provision of community-based services	very much
(3) increasing access to assistive technologies that can support the disabled to live independently	very much
Developing action plans to close down residential institutions	very much
Retraining and requalification of staff working in institutions to provide them with skills for community-based care	very much
Setting minimum quality standards for care services	very much
Providing persons with disabilities with personal budgets	very much
Awareness-raising activities to make the right of people with disabilities to live in the community more socially acceptable	clearly
<b>2.6.2 Compared to now, how much should the following contribute to ensuring persons with disabilities enjoy the right to <u>live independently</u>?</b>	
European Union	much more
National government	much more

Regional/local government	much more
NGOs, including disability NGOs	more
Private sector	more
Other	more
2.6.3 If you choose "Other", please specify Social partners (work/life balance for family carers, working conditions/training for professionals)	
<b>2.7 Thematic areas: PARTICIPATION IN DEMOCRATIC AND PUBLIC LIFE</b>	
<b>2.7.1 How useful are the following in enabling persons with disabilities to <u>participate in democratic and public life</u>?</b>	
Providing policy-related information in accessible formats	very useful
Ensuring elections and voting, including related material, are fully accessible	very useful
Media action to improve the image of persons with disabilities	useful
Providing support to disability NGOs	very useful
<b>2.7.2 Compared to now, how much should the following contribute to ensuring persons with disabilities enjoy the right to <u>participate in democratic and public life</u>?</b>	
European Commission	more
National government	much more
Regional/local government	much more
Disability NGOs	much more
Industry	more
Other	
2.7.3 If you choose "Other", please specify	
<b>2.8 Thematic areas: CULTURE, RECREATION, LEISURE, SPORT</b>	
<b>2.8.1 How useful are the following in enabling persons with disabilities to participate in <u>cultural life, recreation, leisure and sport</u>?</b>	
Providing cultural material and programmes in accessible formats	very useful
Ensuring that cultural venues and monuments and sites of cultural value are accessible	very useful
Supporting the development of creative activities for persons with disabilities	very useful
Providing funding to address disability issues in sports	useful

Ensuring that sports-related facilities are accessible	very useful
Ensuring that sports staff concerned are trained in disability issues	useful
<b>2.8.2 Compared to now, how much should the following contribute to ensuring persons with disabilities enjoy the right to participate in <u>cultural life, recreation, leisure and sport</u>?</b>	
European Union	more
National government	much more
Regional/local government	much more
NGOs, including disability NGOs	more
Private sector	much more
Other	
2.8.3 If you choose "Other", please specify	
<b>2.9 Thematic areas: STANDARDS OF LIVING AND SOCIAL PROTECTION</b>	
<b>2.9.1 How useful are the following to ensuring persons with disabilities enjoy an adequate <u>standard of living and social protection</u>?</b>	
Expanding job opportunities	very useful
Compensating for extra costs and burdens caused by disability in everyday life	very useful
Providing adequate disability pensions	very useful
Measuring the situation of persons with disabilities when gathering data on the groups most vulnerable to poverty	useful
Expanding public housing opportunities for persons with disabilities	very useful
<b>2.9.2 Compared to now, how much should the following contribute to ensuring adequate <u>standards of living and social protection</u>?</b>	
European Union	much more
National government	much more
Regional/local government	much more
NGOs, including disability NGOs	same
Private sector	same
Other	
2.9.3 If you choose "Other", please specify	
<b>2.10 Thematic areas: FREEDOM AND DIGNITY</b>	

**2.10.1 How useful are the following in guaranteeing freedom and dignity for persons with disabilities?**

Developing legislation to ensure persons with disabilities have full legal capacity	very useful
Supporting people with disabilities in decision-making (e.g. in financial transactions and medical treatment options) by: (1) developing legislation	very useful
(2) developing practical tools	very useful
Preventing violence, ill-treatment and abuse of persons with disabilities by: (1) developing legislation (e.g. criminal law)	somewhat useful
(2) developing practical tools (e.g. supporting services, training for families and formal carers)	very useful
Monitoring relevant legal practice in the Member States	useful
Raising awareness of the situation of persons with disabilities	useful

**2.10.2 Compared to now, how much should the following contribute to guaranteeing freedom and dignity for persons with disabilities?**

European Union	much more
National government	much more
Regional/local government	much more
NGOs, including disability NGOs	more
Private sector	more
Other	more

2.10.3 If you choose "Other", please specify  
Social partners (working conditions / training of professional carers)

**3. GOVERNANCE ISSUES**

**How important are the following to the coordination and management of disability policies? ?**

Assigning clear political responsibility for disability at all governance levels	very important
Identifying a lead office for disability issues	very important
Developing communication and cooperation mechanisms between different actors (EU, national and local governments, civil society)	very important
Establishing indicators and targets to measure improvements in the situation of persons with	very important

disabilities	
Assessing the impact of new policies on persons with disabilities	very important
Harmonising rules and standards for accessible goods and services	very important
Increasing financial support for disability matters	very important
Identifying resources dedicated to disability purposes within funding schemes more clearly	important
Developing strategies for communication and awareness-raising on disability issues	very important
Harmonising definitions of disability in the EU	very important
Improving the stability of disability objectives in agenda-setting	very important
Improving possibilities of legal recourse for persons with disabilities	important
<b>4. THE ROLE OF THE EU</b>	
<b>How suitable would the following be in meeting disability-related objectives at EU level?</b>	
Adopting European legislation, which harmonises disability-related objectives across the Member States	suitable
Setting targets and indicators to compare Member State performance	very suitable
Monitoring and evaluating the situation of persons with disabilities (including collection of statistics and research projects)	very suitable
Helping the Member States to exchange information and best practice	very suitable
Providing financial support to disability NGOs	very suitable
Providing financial support to local projects on disability-related issues	very suitable
Supporting research and development programmes and studies	suitable
Developing information and publicity and acceptance campaigns	suitable
Ensuring that goods and services purchased by public authorities and infrastructure built for the public are more usable by and accessible to persons with disabilities	very suitable

Which of these three statements is closest to your view on how the EU should work on disability issues: Both approaches should be used in combination

**5. ANY OTHER REMARKS**

If you have any remarks that you have not been able to make while answering the questions, please put them here (maximum 1500 characters):  
COFACE will soon submit a short additional paper.