

Exmos. Membros da 10ª **Comissão - CTSSI XV**

Ex.ma Senhora

Deputada Clara Marques Mendes

Coordenadora do Grupo de Trabalho – Primeira Alteração ao Estatuto do Cuidador Informal

Agradecemos o pedido de pronúncia do Mecanismo Nacional de Monitorização da Implementação da Convenção sobre os Direitos das Pessoas com Deficiência (Me-CDPD) sobre o Projeto de Lei n.º 816/XV/1.º, para alterar o Estatuto do Cuidador Informal. Enviamos em anexo o parecer deste Me-CDPD e

Os melhores cumprimentos em nome do Mecanismo Me-CDPD

Vera Bonvalot

Presidente do Mecanismo Nacional de Monitorização
da Implementação da Convenção sobre os Direitos das Pessoas com Deficiência (Me-CDPD)





Me-CDPD

Mecanismo Nacional de Monitorização
da Implementação da Convenção sobre
os Direitos das Pessoas com Deficiência

PARECER n.º 1/Me-CDPD/2024

Ex.ma Senhora

Deputada Clara Marques Mendes

Coordenadora do Grupo de Trabalho – Primeira Alteração ao Estatuto do Cuidador

Informal

Assunto: *Convite a pronúncia escrita no âmbito do Grupo de Trabalho - Primeira Alteração ao Estatuto do Cuidador Informal da 10.ª Comissão Parlamentar*

Agradecemos o pedido de pronúncia do Mecanismo Nacional de Monitorização da Implementação da Convenção sobre os Direitos das Pessoas com Deficiência (Me-CDPD) sobre o Projeto de Lei n.º 816/XV/1.º, para alterar o Estatuto do Cuidador Informal.

Está em causa uma matéria de enorme importância para as pessoas com deficiência em Portugal, e que importa analisar, exaustivamente, à luz das disposições da Convenção sobre os Direitos das Pessoas com Deficiência.

Alguns aspetos do Projeto de Lei suscitam-nos especial preocupação, a saber:

1. Alguma aparente confusão entre *cuidador informal* e *acompanhante*;
2. A persistência das fragilidades ainda resultantes do Regime do Maior Acompanhado, suscetíveis de colidir com o pleno exercício da capacidade jurídica das pessoas com deficiência, à luz do disposto no artigo 12.º da Convenção sobre os Direitos das Pessoas com Deficiência;
3. A necessidade de deixar absolutamente clara a diferença entre os estatutos de *cuidador informal* e *assistente pessoal*, mesmo que a função de cuidador



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informal não careça de ser necessariamente assegurada por familiares ou por quem viva com a pessoa cuidada;

4. O facto de as alterações legislativas propostas, mesmo não colidindo com o articulado da Convenção, podem beneficiar de uma redação que seja um reflexo mais ajustado da figura do cuidador informal na CDPD¹.

Muito útil seria, estamos em crer, debater estes e outros aspetos suscitados pelo Projeto de Lei n.º 816/XV/1º.

Mesmo tendo presente o anúncio da muito próxima dissolução da Assembleia da República, o Mecanismo Nacional de Monitorização da Implementação da Convenção sobre os Direitos das Pessoas com Deficiência disponibiliza-se para reunir com o Grupo de Trabalho – Primeira Alteração ao Estatuto do Cuidador Informal, no sentido de participar na indispensável reflexão inerente a uma eventual alteração do Estatuto do Cuidador Informal.

O Me-CDPD agradece e nota que, nesta consulta, foi cumprido o disposto na alínea a) do n.º 2 do artigo 3.º da Lei n.º 71/2019, de 2 de setembro.

Não obstante, chama-se a atenção para o facto de que, para além do Me-CDPD, dever ser promovida a audição das próprias pessoas com deficiência, designadamente através das respetivas organizações representativas, e em particular das que têm carácter de representatividade genérica, conforme resulta do disposto no n.º 3 do artigo 4.º da Convenção das Nações Unidas sobre os Direitos das Pessoas com Deficiência, e que melhor assegura o direito previsto nos artigos 3.º e 4.º da Lei n.º 127/99, de 20 de agosto (Lei das Associações de Pessoas Portadoras de Deficiência), e no Decreto-Lei n.º 106/2013, de 30 de julho (que define o estatuto das organizações não governamentais das pessoas com deficiência).

¹ CRPD/C/27/D/51/2018



Me-CDPD

Mecanismo Nacional de Monitorização
da Implementação da Convenção sobre
os Direitos das Pessoas com Deficiência

Apresentamos os nossos melhores cumprimentos,

Vera Bonvalot

Presidente do Mecanismo Nacional de Monitorização da Implementação da Convenção sobre os Direitos das Pessoas com Deficiência (Me-CDPD)



Lisboa, 5 de janeiro de 2024

ANEXO

Conclusão e recomendação do Comité das Nações Unidas sobre os Direitos das Pessoas com Deficiência CRPD/C/27/D/51/2018



Convention on the Rights of Persons with Disabilities

Distr.: General
31 January 2023

Original: English

Committee on the Rights of Persons with Disabilities

Views adopted by the Committee under article 5 of the Optional Protocol, concerning communication No. 51/2018*.**

<i>Communication submitted by:</i>	Maria Simona Bellini (represented by counsel, Andrea Saccucci)
<i>Alleged victims:</i>	The author, Letizia Costanzo and Salvatore Lentini
<i>State party:</i>	Italy
<i>Date of communication:</i>	28 March 2017 (initial submission)
<i>Document references:</i>	Decision taken pursuant to rule 70 of the Committee's rules of procedure, transmitted to the State party on 12 April 2018 (not issued in document form)
<i>Date of adoption of Views:</i>	26 August 2022
<i>Subject matter:</i>	Lack of legal recognition of and social support for family caregivers of persons with disabilities
<i>Procedural issues:</i>	Exhaustion of domestic remedies; substantiation of claims
<i>Substantive issues:</i>	Equality and non-discrimination; awareness- raising; equal recognition before the law; freedom from exploitation, violence and abuse; living independently and being included in the community; respect for the family; health; adequate standard of living and social protection
<i>Articles of the Covenant:</i>	5, 8, 12, 16, 19, 23, 25 and 28
<i>Article of the Optional Protocol:</i>	2 (d)–(e)

1. The author of the communication is Maria Simona Bellini, a national of Italy born in 1957. She is a family caregiver to her daughter, Letizia Costanzo born in 1988, and to her partner, Salvatore Lentini born in 1956, both of whom are Italian nationals and persons with disabilities. The author submits the communication on her own behalf and on behalf of her daughter and partner. She claims that the Italian legal system does not provide for any legal

* Adopted by the Committee at its twenty-seventh session (15 August–9 September 2022).

** The following members of the Committee participated in the examination of the communication: Rosa Idalia Aldana Salguero, Abdelmajid Makni, Danlami Umaru Basharu, Gerel Dondovdorj, Gertrude Oforiwa Fefoame, Vivian Fernández de Torrijos, Odelia Fitoussi, Mara Cristina Gabrielli, Amalia Gamio Ríos, Samuel Njuguna Kabue, Rosemary Kayess, Kim Mi Yeon, Sir Robert Martin, Floyd Morris, Jonas Ruskus, Markus Schefer, Saowalak Thongkuay and Risnawati Utami.



status and protection for family caregivers, in violation of articles 5, 8, 12, 16, 19, 23, 25 and 28 of the Convention. The Optional Protocol entered into force for the State party on 14 June 2009. The author is represented by counsel.

A. Summary of the information and arguments submitted by the parties

Facts as submitted by the author

2.1 The author is a caregiver to her daughter, Ms. Costanzo, and her partner, Mr. Lentini. Her daughter has been diagnosed with brachycephaly, quadriplegia with generalized hypotony, myoclonic epilepsy, intellectual disabilities, food and sleep disorders, ataxia, total absence of verbal language, cyclic vomiting syndrome, uncontrollable drooling and self-injurious behaviour. The author deals with all aspects of her daughter's daily life, such as her personal hygiene, medication, postural changes, feeding, use of rehabilitative aids, cleaning the home environment, daily changes of bed linen and night care. She also accompanies her daughter to a specialized day centre from 9.30 a.m. to 2.30 p.m., Monday to Friday, and from 9.30 a.m. to 12.00 p.m. on Saturday, to assist her daughter at the centre. At night, the author is often forced to stay awake to watch over her daughter and handle epileptic attacks and vomit crises. As her daughter is also affected by self-injurious behaviour, including biting her tongue and hands as result of which she has undergone several reconstructive surgeries, the author is often forced to keep a finger in her mouth to prevent her from biting, even at night.

2.2 In the last decade, the author has also cared for her partner. In 2007, after five years of their relationship, her partner had a brain haemorrhage, which led to a coma. The consequences for his health were severe. He has been diagnosed with diabetes, hypertension, cerebral ataxia, lack of balance and mobility, memory lapses and depression. He needs continuous assistance with hygiene, medication, meals and walking.

2.3 The author also assists her daughter and her partner by managing all their relations with institutions, such as the municipality, the Department of Social Services, hospitals, school, rehabilitation centres, credit institutes and centres for autonomy, for the delivery of services, benefits, family support, visits and medical care. She also deals with various administrative requirements.

2.4 The author invests her remaining time and efforts in improving her medical and legal knowledge related to disability issues. To sustain the necessary income, she works from home by telecommuting. She has been allowed to telecommute since 2013 as her office work was incompatible with the assistance necessary for her daughter and partner. However, her telecommuting rights were revoked in January 2017, preventing her from continuing her employment.

2.5 The author notes that, under article 1 of the Optional Protocol, the Committee has a mandate to receive and consider communications from or on behalf of individuals or groups of individuals who claim to be victims of a violation by the State party of the provisions of the Convention. The author argues that, under article 1 of the Optional Protocol, she also has standing in her capacity as a family caregiver of persons with disabilities. This is based on three linked arguments, namely: (a) the fundamental connection that exists between her as the carer and the persons with disabilities; (b) that caring activities without any legal recognition is a form of discrimination; and (c) that caring is a substantive human right.

2.6 The author also serves as the President of Coordinamento Nazionale Famiglie Disabili Gravi e Gravissimi (hereinafter, "the Association"), founded in 2007. The Association is committed to the promotion of all persons with disabilities and family caregivers' rights and aims to encourage a widespread knowledge of laws, administrative procedures, care and facilities, and to enhance communication between families and institutions. In the past decade, the Association has carried out several initiatives to request the State party to provide legal protection to family caregivers. The Association filed a petition to the Parliament of Italy, which was signed by 200,000 individuals, asking for the introduction of legislation concerning the status and entitlements of family caregivers. With the support of the Association, the author and other family caregivers launched a lawsuit against the National

Social Security Institute, claiming the payment of social security benefits. However, courts in Milan and Rome rejected the lawsuits. In the past decade, several bills concerning family caregivers have also been introduced in both Houses of Parliament, however, the deliberations regarding the bills have not been concluded and no bill has entered into force.

2.7 Due to the inaction of the legislator, the Association, joined by some 30,000 individuals, also petitioned the European Parliament. As a result, a hearing was held on 17 September 2015, drawing great attention to the issue. Following the hearing, the Chair of the Committee on Petitions wrote to the Minister of Health of Italy in order to learn about the authorities' response to the requests made.

2.8 The author states that, at present, the legal system in the State party does not provide any legal protection to family caregivers regarding pensions for assistance, indemnity or sickness insurance. This lack of legal recognition and support leaves family caregivers, such as the author, at risk of experiencing negative and heavy consequences for their health, finances, socioeconomic situation, and personal and social life. Due to this lack of legal recognition, the author is a victim of impoverishment. She is not entitled to receive compensation or economic support for the care that she provides to her daughter and partner. The only form of care allowance recognized in the State party is a very small allowance for the person with disabilities. As she can no longer telecommute, the author notes that she will lose her job and the related income, as she needs to be at home in order to be able to care for her daughter and partner. She further notes that, as a family caregiver, she is forced to sustain direct and indirect costs associated with the provision of care. Moreover, the fact that she will no longer be able to work and earn an income will have long-term effects on her pension entitlements.

2.9 The author submits that, due to this gap in legislation, there are no effective domestic remedies available that could redress the violations of her and her relatives' rights under the Convention. As such, exhaustion of other general remedies would not be effective as the rights of family caregivers are not recognized.

Complaint

3.1 The author claims that the lack of legal recognition of and support for family caregivers has resulted in a violation of her, her daughter's and her partner's rights under articles 5, 8, 12, 16, 19, 23, 25 and 28 of the Convention.

Article 5

3.2 The author argues that the legal vacuum characterizing the Italian legal system leaves family caregivers vulnerable and exposed to "discrimination due to association" in violation of article 5 of the Convention. She claims that she has been closely associated with the family members she cares for and that she has, as a result, experienced discrimination in the labour market, as shown by the revocation of her right to telecommute and the prospective loss of her employment. She adds that combining paid work and caring activities is difficult for caregivers, forcing them to take up part-time work or leave the labour market entirely, with serious financial consequences and costs for the family as a result. She also claims that she has faced gender discrimination as most family caregivers are women. She argues that the State party is under an obligation to take all appropriate steps to avoid discrimination and achieve substantial equality, including specific measures and positive actions to the benefit of persons with disabilities and their families.

Article 8

3.3 The author submits that the facts of the communication amount to a violation of article 8 of the Convention on account of the lack of professional counselling, information and official recognition of the skills of family caregivers. She claims that she has not received any information from the public authorities that could help her in fulfilling her role as a caregiver, especially as regards the criteria for access to social benefits and to social and health-care services in the home. She argues that family caregivers need professional counselling on how to address the needs of persons with disabilities to ensure awareness and freedom of choice in caring and to provide specific and high-quality assistance. However,

family caregivers are often left without assistance and support from the authorities, including when it comes to carrying out medical activities, such as the changing of tracheobronchial or nasal-tracheal aspiration, and cardiopulmonary resuscitation. She argues that the State party should set up special training programmes aimed at improving the quality of care given at home and at formalizing the competence of caregivers at the national level.

Article 12

3.4 The author claims a violation of article 12 of the Convention due to the failure by the State party to recognize the status of family caregivers. She argues that interpreting article 12 in the light of the right to live in the community means that support in the exercise of legal capacity should be provided through a community-based approach. As such, it is important that the key role of family caregivers is recognized, as only through this approach will it be possible to achieve full inclusion and participation of persons with disabilities in the community. The author further argues that, in situations as those of her family members, legal capacity is exercised by the family caregivers but the State party's legal system does not recognize their status or role, and does not provide any specific forms of training, assistance or preparation for such a role.

Article 16

3.5 The author asserts that the State party does not prevent the psychological and physical exhaustion of family caregivers, due to the lack of specific preventive measures that enable them to reconcile work, assistance and family life, in violation of article 16 of the Convention. She argues that, if family caregivers are not in a position to fully meet the needs of the assisted person, the latter risks becoming the victim of neglect or abuse.

Article 19

3.6 The author claims that the lack of legal recognition of family caregivers has serious consequences for the rights of persons with disabilities, including her family members, to live independently in the community and to achieve inclusion and participation in society, in violation of their rights under article 19 of the Convention. She argues that, in accordance with the provisions of article 19, persons with disabilities should have the right to decide where and with whom to live and not be obliged to accept a particular living arrangement. She maintains that persons with disabilities and their families have the right to make decisions about their lives and be granted support based on their specific needs. The protection of independent living and inclusion in the community requires that the State party provide services supporting families, especially caregivers. The support should not be reduced to the simple payment of allowances, although she notes that in the State party not even this is provided for as family caregivers are not entitled to receive economic support, with only a small care allowance being provided to the person with disabilities. She notes that her family members need affordable day-care services, home help, respite care, night care, guidance and counselling, education and development of skills.

Article 23

3.7 The author further claims that the State party does not allocate specific financial, social and other resources to ensure that families have access to the necessary support, in violation of article 23 of the Convention. She holds that article 23 imposes on the State party an obligation to adopt measures in the form of financial aid, varying in accordance with the needs of persons with disabilities in order for them to be able to live with their families and not to be placed in institutions. She submits that this lack of appropriate measures in support of her family amounts to a violation of article 23 of the Convention.

Article 25

3.8 The author also asserts that her rights and the rights of her family members under article 25 of the Convention have been violated as the legal system of the State party does not recognize the role of the family caregiver in the health system. She argues that the health needs of persons with disabilities require harmonious cooperation between the family caregiver and health professionals.

Article 28

3.9 The author also claims that article 28 of the Convention has been violated as the State party does not recognize any form of social protection or insurance for family caregivers. In addition, no form of social benefits are granted in a situation like hers, when family caregivers lose their employment due to their activities as caregivers. She argues that, as a result, families of persons with disabilities face a high risk of poverty. For this reason, they are in particular need of social protection in terms of resources, time and services. She notes that measures aimed at improving the living conditions of persons with disabilities and their families may assume different forms, such as compensation for expenses, more favourable access to housing, care services that are financially accessible, favourable tax rates, flexible working hours and access to workplaces that are located close to the home, recognition of the status of caregiver in the pension system, and protection against discrimination at work and arbitrary dismissal. She notes, however, that none of these measures are available in the State party and no adequate social security measure is provided to the family.

Requested remedies

3.10 The author requests that the Committee declare that the State party has violated its obligations under articles 5, 8, 12, 16, 19, 23, 25 and 28 of the Convention, and recommend that it adopt all necessary measures to comply with the Committee's findings and to provide the author's family with an effective remedy, including the reimbursement of any legal costs incurred, together with compensation.

State party's observations on admissibility and the merits

4.1 On 12 June and 12 October 2018, the State party submitted its observations on admissibility and the merits of the communication. It submits that the communication should be declared inadmissible as it is manifestly unfounded and for failure to exhaust domestic remedies.

4.2 The State party notes that the author, with the support of the Association, filed a lawsuit against the National Social Security Institute requesting the payment of social security and social benefits before courts in Milan and Rome. It notes that the courts rejected the lawsuits on 15 July and 14 October 2014, respectively. The State party argues that, in order to exhaust domestic remedies, the author should have appealed these decisions. It also argues that the author should have "activated the measure for judicial protection" under Law No. 67 of 1 March 2006 (on provisions for judicial protection of persons with disabilities, victims of discrimination), as she has raised claims of discrimination in the labour market due to the revocation of her right to telecommute.

4.3 As regards the merits of the complaint, the State party submits that different forms of protection are provided under its domestic legislation. First, three days paid leave under article 33 of Law No. 104 of 5 February 1992 (on assistance, social integration and the rights of persons with disabilities) for public or private employees who assist family members with severe disabilities. Second, extraordinary paid leave from work as provided for under article 42 of Legislative Decree No. 151 of 26 March 2001, which is granted for a period of two years for an employee who assists a person with disabilities. The caregiver is entitled to an allowance corresponding to the last salary and the period is covered by an imputed social contribution. Third, a fund for dependent persons as regulated under article 1 of Law No. 296 of 27 December 2006, which provides support to family members of persons with disabilities. Under the regulations, financial assistance to purchase home care and assistance services may be provided, as well as for admissions to residential care for respite care. Fourth, a "fund to support the caregiving and assistance role of the family caregiver" established under article 1 (254) of Law No. 205 of 27 December 2017, which has allocated 20 million euros annually for 2018, 2019 and 2020 to cover the financial costs of legislative interventions aimed at recognition of the social and economic value of family caregivers. Fifth, Legislative Decree No. 151, under which longer parental leave, of up to three years, is offered to parents of a child with disabilities.

Author's comments on the State party's observations on admissibility and the merits

5.1 On 21 December 2018, the author submitted her comments on the State party's observations on admissibility and the merits of the communication. She maintains that the communication is admissible.

5.2 Regarding the exhaustion of domestic remedies, the author argues that the claims raised in the communication stem directly from domestic law, or rather from the failure by the State party to provide an adequate legal framework for the recognition of the role of family caregiver. She submits that, for this reason, no judicial mechanism can be considered to be effective within the meaning of article 2 (d) of the Optional Protocol.

5.3 The author refers to the applications filed by her and other family caregivers before the Tribunal of Rome and the Tribunal of Milan, on 3 and 26 February 2014, respectively, in which they claimed that the State should pay the social security contributions of family caregivers. The author notes that she only pursued this action in order to obtain some form of legal recognition for the working activities carried out as a caregiver. She requested the courts to extend the rules applicable to other protected categories to family caregivers. In particular, she claimed the payment of social contributions and benefits, as well as compulsory insurance against accidents, illness and third-party liability. In its judgment of 15 July 2014, the Tribunal of Milan explicitly recognized the existence of a structural problem in the Italian legal system, finding that "the problem herein submitted to the attention of the judicial authority, considering its contents and scope, should be solved by Parliament". The Tribunal further noted that, as the legal status of family caregivers was not provided for by law, "surely it cannot be created by the jurisprudence". The author argues that, consequently, an appeal would not have had any prospect of success. She notes the jurisprudence of the European Court of Human Rights in *Oliari and others v. Italy*,¹ in which the Court noted that domestic courts "could not but invite the legislature to take action" and that therefore "the applicants cannot be blamed for not having pursued an ineffective remedy, either at all or until the end of the judicial process". The author further notes that under domestic law an individual is not entitled to apply directly to the Constitutional Court for review of a law's constitutionality or to complain about the absence of legislative measures. Domestic courts may interpret and apply legislation in force but they do not have the power to alter existing legislation.

5.4 Regarding the State party's argument concerning the remedy provided for in Law No. 67 for victims of discrimination, the author argues that this reference is misleading. It does not pertain to the situation of the author and her family regarding legal recognition for family caregivers, but rather proceedings concerning alleged discrimination of persons with disabilities related to employment and working conditions.

5.5 The author notes that the State party has referred to a number of legislative acts (see para. 4.3 above) that it argues provide protection for family caregivers. The author reiterates her argument that the State party's legal system, including the measures referred to by the State party, does not offer any effective measures of social security to support family caregivers, such as compensation for expenses, access to housing, financially accessible care services, a favourable tax regime, flexible working hours and access to workplaces close to home, recognition of the status of caregiver in the pension system and protection against discrimination and arbitrary dismissals in the labour market. She notes that the State party has referred to the provisions of article 33 of Law No. 104, according to which caregivers have the right to three days of paid leave from work each month and the corresponding social security contributions would be covered by the State. She notes that this is clearly far from sufficient to address the needs, such as those of her family members, of permanent, continuous assistance. She also notes the State party's information that parental leave is extended for up to three years for parents who have children under 12 years with severe disabilities. She notes that this legislation is not applicable to her situation as her daughter is an adult. As regards the State party's information on the possibility of extraordinary paid leave from work under Legislative Decree No. 151, the author notes that this is an extraordinary measure, which can only be granted once in a lifetime and at most for a period

¹ Application Nos. 18766/11 and 36030/11, Judgment, 21 July 2015, paras. 82–83.

of two years. It is not a measure that would remedy her situation as her daughter and partner require continuous, uninterrupted and attentive care. The author also observes that the State party refers to the fund for dependent persons. She argues that this measure again failed to formally recognize and regulate the category of family caregivers. She notes that economic support under the fund is fragmented and limited in scope, with the economic resources available often earmarked for specific services. She finally notes that the State party has also made reference to a fund created to support the caregiving and assistance role of family caregivers. She argues that the information provided by the State party is incomplete and misleading as the Ministry of the Economy and Finance has not approved the necessary changes in the financial budget in order to allocate resources to implement the fund. As such, the fund formally exists, but has not been put into effect, and no form of redress or compensation has been provided to family caregivers such as the author.

B. Issues and proceedings before the Committee

Consideration of admissibility

6.1 Before considering any claim contained in a communication, the Committee must decide, in accordance with article 2 of the Optional Protocol and rule 65 of its rules of procedure, whether the communication is admissible under the Optional Protocol.

6.2 The Committee has ascertained, as required under article 2 (c) of the Optional Protocol, that the same matter has not already been examined by the Committee, and that it has not been, nor is it being, examined under another procedure of international investigation or settlement.

6.3 The Committee notes the State party's argument that the communication should be found to be inadmissible for failure to exhaust domestic remedies as the author did not appeal the decisions of the Tribunals of Milan and Rome of 15 July and 14 October 2014, respectively, to reject the author's claims for payment of family caregivers' social security contributions. It also notes the State party's submission that the author should have applied for judicial protection under Law No. 67, concerning her claims of discrimination in the labour market due to the revocation of her right to telecommute. The Committee also notes the author's argument that the claims raised in the communication stem directly from the failure by the State party to provide an adequate legal framework for the recognition of the status of family caregivers and that, as such, no judicial mechanism can be considered to be effective within the meaning of article 2 (d) of the Optional Protocol.

6.4 The Committee recalls its jurisprudence that, although there is no obligation to exhaust domestic remedies if they have no reasonable prospect of being successful, authors of communications must exercise due diligence in the pursuit of available remedies, and that mere doubts or assumptions about the effectiveness of domestic remedies do not absolve authors from exhausting them.²

6.5 The Committee notes the author's information that, in its decision of 15 July 2014, the Tribunal of Milan explicitly recognized the existence of a structural problem in the Italian legal system, however, finding that this structural problem could not be remedied by judicial authorities considering its content and scope, but only through legislative acts by Parliament. The Committee also notes the author's argument that, under domestic law, an individual is not entitled to apply directly to the Constitutional Court for review of a law's constitutionality or to complain about the absence of legislative measures. Furthermore, it notes the author's argument that the remedy provided for in Law No. 67 for victims of discrimination does not pertain to the situation of the author and her family regarding legal recognition for family caregivers, but rather proceedings concerning alleged discrimination of persons with disabilities related to employment and working conditions. The Committee notes that the State party has not refuted any of the author's information regarding the decision of the

² *D.L. v. Sweden* (CRPD/C/17/D/31/2015), para. 7.3; *E.O.J. et al. v. Sweden* (CRPD/C/18/D/28/2015), para. 10.6; and *T.M. v. Greece* (CRPD/C/21/D/42/2017), para. 6.4. See also *V.S. v. New Zealand* (CCPR/C/115/D/2072/2011), para. 6.3; *García Perea v. Spain* (CCPR/C/95/D/1511/2006), para. 6.2; and *Vargay v. Canada* (CCPR/C/96/D/1639/2007), para. 7.3.

Tribunal of Milan, the possibility for an individual to submit an application before the Constitutional Court or the remedies provided for in Law No. 67 for victims of discrimination. Nor has the State party provided any information on the possibilities for a successful appeal of the decisions of the Tribunals of Milan and Rome of 15 July and 14 October 2014, taking into account that the rejection of the author's initial lawsuit before such tribunals stemmed from the lack of domestic legislation recognizing the status of family caregivers. Considering the facts referred to above, the Committee therefore finds that it is not precluded by article 2 (d) of the Optional Protocol from considering the present communication.

6.6 The Committee also notes the State party's submission that the communication should be declared inadmissible as being manifestly ill-founded under article 2 (e) of the Optional Protocol. It notes the author's claims that the lack of legal recognition of and support for family caregivers has resulted in a violation of her, her daughter's and her partner's rights under articles 5, 8, 12, 16, 19, 23, 25 and 28 of the Convention. The author has further claimed that she has standing under article 1 of the Optional Protocol to bring claims on her own behalf in her capacity of family caregiver based on three linked arguments, namely: (a) that a fundamental connection exists between the carer and the person with disabilities; (b) that caring activities without any legal recognition is a form of discrimination; and (c) that caring is a substantive human right.

6.7 The Committee notes that, under article 1 of the Optional Protocol, it has a mandate to receive and consider communications from or on behalf of individuals or groups of individuals who claim to be victims of a violation by the State party of the provisions of the Convention. The Committee recalls its jurisprudence that, under article 1 of the Convention, persons with disabilities include, but are not limited to, those who have long-term physical, mental, intellectual or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. The Committee considers that the difference between illness and disability is a difference of degree and not a difference of kind. A health impairment that initially is conceived of as illness can develop into an impairment in the context of disability as a consequence of its duration or its chronicity. A human rights-based model of disability requires that the diversity of persons with disabilities be taken into account (preamble, para. (i)) together with the interaction between individuals with impairments and attitudinal and environmental barriers (preamble, para. (e)).³ In the present case, it is clear that the information provided by the parties does not preclude the Committee from considering that the impairments of the author's daughter and partner, in interaction with barriers, may hinder their full and effective participation in society on an equal basis with others within the meaning of article 1 of the Convention.

6.8 The Committee notes that the author has not claimed that she herself has a long-term physical, mental, intellectual or sensory impairment within the meaning of article 1 of the Convention. Therefore, with regard to the author's claims based on her own rights, the Committee must determine whether the Convention protects the rights of individuals other than persons with disabilities, and whether the violation of such rights can be claimed under the Optional Protocol. The Committee recalls that, as stated in article 1 of the Convention, the purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights of persons with disabilities. However, the Committee is aware of instances in which the rights of persons with disabilities cannot be realized without the protection of family caregivers. In this regard, it notes that the Convention in its preamble (para. (x)) states that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and 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. In keeping with the purpose of the Convention, as stated in article 1, article 28 (1) of the Convention recognizes the right of persons with disabilities to an adequate standard of living for themselves and their families. However, article 28 (2) (c) explicitly requires States parties to ensure access by persons with disabilities and their families to assistance, in order to

³ *S.C. v Brazil* (CRPD/C/12/D/10/2013), para. 6.3; and *Sherlock v. Australia* (CRPD/C/24/D/20/2014), para. 8.6.

safeguard and promote the right of persons with disabilities to social protection. This text – in the drafting process originally contained in what is today article 23 – suggests that, in the narrow context of article 28 (2) (c), the Convention confers on family members of persons with disabilities the right to assistance from the State. This right, as all other rights guaranteed by the Convention, aims at fulfilling the purpose of the Convention as stated by article 1. Therefore, the right of family members under article 28 (2) (c) must be indivisibly linked to the protection of the rights of family members with disabilities. Article 28 (2) (c) confers a right on family members who do not have a disability under the condition that such a right is a necessary prerequisite for the realization of the rights of family members with disabilities and that denying such a right would have a direct negative impact on the rights of family members with disabilities. The fulfilment of these prerequisites needs to be assessed on a case-by-case basis. As this Committee has stated in its general comment No. 6 (2018) (para. 20), the reason for incorporating the concept of “discrimination by association” into the Convention is to eradicate and combat all discriminatory situations and/or discriminatory conduct linked to disability.

6.9 In light of the above, the Committee considers that, in the specific circumstances of the present case, the author has sufficiently substantiated, for the purposes of admissibility, that assistance by the State to her as family caregiver based on article 28 (2) (c) was a necessary condition for the realization of the rights of her daughter and her partner with disabilities with whom she is living in a family, that the enjoyment of their rights was indivisibly linked to the recognition of the author’s rights under article 28 (2) (c) and that the lack of such support would have a direct negative impact on the rights of her daughter and partner. Having reached this conclusion, the Committee considers that it is not precluded by article 1 of the Optional Protocol to consider the claims presented by the author on behalf of her daughter and partner and, as far as her claim based on article 28 (2) (c) of the Convention is concerned, on her own behalf, all read in conjunction with article 5.

6.10 The Committee notes the author’s claims that the lack of recognition for family caregivers amounts to a violation of article 16 of the Convention and her claim that her rights and the rights of her family members under article 25 of the Convention have been violated as the legal system of the State party does not recognize the role of the family caregiver in the health system. It, however, notes that the author has not provided any further information or argumentation to substantiate these claims, and therefore finds them to be inadmissible for lack of substantiation under article 2 (e) of the Optional Protocol.

6.11 The Committee also notes the author’s claims of a violation of article 8 of the Convention on account of the lack of professional counselling and information provided to caregivers and the lack of official recognition of their skills as caregivers. It also notes her claims of a violation of article 12 of the Convention due to the failure by the State party to recognize the status of family caregivers. The Committee, however, notes that the author raises these claims as a violation of her own rights as a caregiver and that she has not provided any specific information on how she considers that the claims raised amount to a violation of the rights of her daughter and partner under these articles. Regarding the claims raised under article 12 of the Convention, the Committee further notes that the author has not claimed that her daughter or partner have been denied legal capacity. The Committee therefore finds the claims raised under articles 8 and 12 of the Convention to be inadmissible for lack of substantiation under article 2 (e) of the Optional Protocol.

6.12 The Committee notes the author’s further claims that: she has been discriminated against in the labour market due to her role as a caregiver, resulting in the loss of her employment and income, in violation of article 5 of the Convention; that the lack of legal recognition of family caregivers has affected the rights of her daughter and partner to live independently in the community and to achieve inclusion and participation in society, in violation of their rights under article 19 of the Convention; and that the State party’s failure to allocate specific financial, social and other resources to the family amounts to a violation of the rights of her daughter and partner under article 23 of the Convention. It further notes her arguments that the lack of legal recognition of family caregivers and the corresponding lack of financial and social protection amounts to a violation of article 28 of the Convention. The Committee understands the claims raised under article 28 of the Convention to be invoked in relation to the family as a whole and to be focused on the alleged lack of assistance

provided by the State party to families of persons with disabilities, such as the author's family, resulting in a high risk of poverty. Taking into account the information provided by the author, the Committee considers that she has sufficiently substantiated the claims raised on behalf of her daughter and partner under articles 19 and 23, as well as the claims raised on behalf of the family – namely, herself and her daughter and partner – under article 28, read in conjunction with article 5, of the Convention for the purposes of admissibility.

6.13 In the absence of any other challenges to the admissibility of the communication, the Committee declares the communication admissible insofar as it concerns the author's claims raised on behalf of her daughter and partner under articles 19 and 23 of the Convention, as well as the claims raised on her own behalf and on behalf of her family members under article 28 (2) (c), read in conjunction with article 5, of the Convention, and proceeds with its consideration of the merits.

Consideration of the merits

7.1 The Committee has considered the present communication in the light of all the information that it has received, in accordance with article 5 of the Optional Protocol and rule 73 (1) of the Committee's rules of procedure.

7.2 The Committee notes the author's claim that the lack of legal recognition of family caregivers has serious consequences for the rights of persons with disabilities, including her family members, to live independently in the community and to achieve inclusion and participation in society, in violation of their rights under article 19 of the Convention. It notes her argument that persons with disabilities should have the right to decide where and with whom to live and not be obliged to accept a particular living arrangement and that persons with disabilities and their families have the right to make decisions about their lives and be granted support based on their specific needs. It also notes the State party's submission that various forms of protection for families of persons with disabilities are provided under its domestic legislation.

7.3 The Committee recalls that, under article 19 of the Convention, States parties shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of the right to live in the community with choices equal to others, and their right to full inclusion and participation in the community, including by ensuring that persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others; that they have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; and that community services and facilities for the general population are available, on an equal basis, to persons with disabilities and are responsive to their needs.

7.4 The Committee further recalls its general comment No. 5 (2017) on living independently and being included in the community, in which it noted that individualized support services must be considered a right rather than a form of medical, social or charity care. Persons with disabilities therefore have the right to choose services and service providers according to their individual requirements and personal preferences, and individualized support should be flexible enough to adapt to the requirements of the "users" and not the other way around.⁴ The Committee has further concluded that the obligation to facilitate full enjoyment by persons with disabilities of the right to live in the community requires States to promote, facilitate and provide appropriate legislative, administrative, budgetary, judicial, programmatic, promotional and other measures to ensure the full realization of the right to live independently and be included in the community as enshrined in the Convention.⁵ The Committee has also emphasized that States parties should empower family members to support family members with disabilities to realize their right to live independently and be included in the community.⁶ Furthermore, the Committee has clarified that disability support services must be available, accessible, affordable, acceptable and

⁴ General comment No. 5 (2017), para. 28.

⁵ *Ibid.*, para. 54.

⁶ *Ibid.*, para. 55.

adaptable to all persons with disabilities and be sensitive to different living conditions, such as individual or family income, and individual circumstances.⁷ Finally, the Committee has emphasized the need for States parties to provide adequate support services to family carers so that they can in turn support their relatives to live independently in the community. This support should include respite care services and other support services.⁸ Additionally, the Committee has found that financial support is also crucial for family carers, who often live in situations of extreme poverty without the possibility of accessing the labour market and that States parties therefore have the obligation to provide social support to families of persons with disabilities and foster the development of counselling services, circles of support and other adequate support options.⁹ The Committee notes that, in its concluding observations on the initial report by the State party, it expressed concern about the trend to re-institutionalize persons with disabilities in the State party and the fact that funds were not being reallocated from institutions to promoting and ensuring independent living for all persons with disabilities within their community. Furthermore, it noted with concern the gendered consequences of these policies in which women were forced to remain within the family as caregivers of their peers with disabilities instead of being employed in the labour market. The Committee recommended that the State party implement safeguards to retain the right to autonomous independent living across all regions, and redirect resources from institutionalization to community-based services and increase budget support to enable persons with disabilities to live independently across the country and have equal access to services, including personal assistance.¹⁰

7.5 In the present case, the Committee notes the author's claim that her lack of legal recognition and support as the family caregiver has affected the rights of her daughter and partner to live independently in the community and to achieve inclusion and participation in society, in violation of their rights under article 19 of the Convention. It notes her information that no support, such as financial support, social support, affordable day-care services, home help, respite care, night care, guidance and counselling, education and skill development have been provided to her family by the State party's authorities. The Committee further notes the State party's argument that different forms of protection are provided under its domestic legislation to families of persons with disabilities, such as three days paid leave for family caregivers; extraordinary paid leave for a period of two years for an employee who assists a person with disabilities; assistance from funds providing support to family members of persons with disabilities; and parental leave of up to three years to parents of a child with disabilities. The Committee notes, however, the author's argument that none of the measures referred to by the State party are relevant to her family situation considering the fact that her family members require continuous assistance. It also notes her argument that none of the measures referred to by the State party offer any effective measures of social security to support family caregivers, such as compensation for expenses, access to housing, financially accessible care services, a favourable tax regime, flexible working hours, recognition of the status of caregiver in the pension system and protection against discrimination and arbitrary dismissals in the labour market. The Committee also notes her information that no form of redress or compensation has been provided to her family to address their situation, including from the funds referred to by the State party.

7.6 The Committee takes note of the author's information that no adequate support services have been provided to her family in order to facilitate the right of her daughter and partner to live in the community with choices equal to others, and their right to full inclusion and participation in the community. It notes that the State party has not refuted the author's claims, apart from providing information on some forms of general support measures not applicable to the family's situation, which are available under domestic legislation. The Committee therefore concludes, based on the information on file, that: the lack of individualized support services provided to the author's daughter and partner; the failure by the State party to promote, facilitate and provide appropriate legislative, administrative, budgetary, judicial, programmatic, promotional and other measures to ensure the full

⁷ Ibid., para. 60.

⁸ Ibid., para. 67.

⁹ Ibid.

¹⁰ [CRPD/C/ITA/CO/1](#), paras. 47–48.

realization of the right to live independently and be included in the community as enshrined in the Convention; and the failure to provide adequate support services to family carers so that they can in turn support their relatives to live independently in the community, including by providing respite care services, other supportive services, financial support, social support, counselling services, and other adequate support options, amount to a violation of the rights of the author and her daughter and partner under article 19 of the Convention.

7.7 The Committee notes the author's claims that the State party does not allocate specific financial, social and other resources to ensure that families of persons with disabilities such as hers have access to the necessary support, in violation of article 23 of the Convention. It notes her argument that article 23 imposes on the State party an obligation to adopt measures in the form of financial aid, varying in accordance with the need of the person with disabilities in order for them to be able to live with their family and not be placed in institutions. The Committee recalls that the right to live independently in the community is intimately linked with the right to family for children and parents with disabilities and that the absence of community-based support and services may create financial pressures and constraints for the family of persons with disabilities.¹¹ The Committee recalls that, in its observations on the State party's initial report, it expressed concern about the lack of specific measures to support families of children with disabilities or adults with high levels of support needs, including financial support. It recommended that the State party allocate specific financial, social and other resources across all regions to ensure that all families with members with disabilities, including those members with high support needs, could gain access to the support that they required, to ensure the right to home and family and to inclusion and participation in their local communities, and to eliminate the need to resort to institutionalization.¹² In the present case, the Committee notes the author's unrefuted claim that her family has not been provided with any specific measure of support, including financial support, to ensure that the right of her daughter and partner to home and family and to inclusion and participation in their local community is safeguarded and to ensure that families in situations like hers are able to avoid resorting to institutionalization. The Committee therefore finds that the failure by the State party to provide the family with adequate support in their right to home and family amount to a violation of the rights of the author's daughter and partner under article 23 of the Convention.

7.8 The Committee notes the author's claims of a violation of the family's rights under article 28 of the Convention as the State party does not recognize any form of social protection or insurance for family caregivers and that, as a result of this lack of legal protection and assistance in the State party, families of persons with disabilities, including the author's family, are at high risk of poverty and are therefore in particular need of social protection in terms of resources, time and services. The Committee recalls that, under article 28 (2) (c) of the Convention, States parties shall take appropriate steps to ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care. It further recalls that, to ensure that persons with disabilities enjoy an adequate standard of living, States parties have an obligation to ensure access to appropriate and affordable services, devices and other assistance for impairment-related requirements, especially for those persons with disabilities who live in poverty. Furthermore, access to public and subsidized housing programmes in the community is required. It recalls that it is considered contrary to the Convention for persons with disabilities to pay for disability-related expenses by themselves.¹³ The Committee further recalls that, in its observations on the State party's initial report regarding article 28 of the Convention, it expressed concern about: regional variations of social protection mechanisms in the State party; the lack of minimum standards of social assistance; the high level of poverty among persons with disabilities and their families in the State party; and the lack of assessment of the adverse effects of austerity measures.¹⁴

¹¹ General comment No. 5 (2017), para. 87.

¹² CRPD/C/ITA/CO/1, paras. 51–52.

¹³ General comment No. 5 (2017), para. 92.

¹⁴ CRPD/C/ITA/CO/1, paras. 71–72.

7.9 The Committee further notes the author's claim that the legal vacuum characterizing the Italian legal system leaves family caregivers vulnerable and exposed to discrimination due to association in violation of article 5 of the Convention. It notes her claims that she has been closely associated with the family members she cares for and discriminated against in the labour market for this reason, as shown by the revocation of her right to telecommute and the loss of her employment and income. The Committee recalls its general comment No. 6 (2018) on equality and non-discrimination, in which it stated that the obligations to prohibit all discrimination on the basis of disability included persons with disabilities and their associates, for example, parents of children with disabilities.¹⁵ The Committee has further noted that discrimination "on the basis of disability" can therefore also be made against persons who are associated with a person with a disability, known as "discrimination by association" and that the reason for the wide scope of article 5 is to eradicate and combat all discriminatory situations and/or discriminatory conduct linked to disability.¹⁶ In this context, the Committee has further emphasized that poverty is both a compounding factor and the result of multiple discrimination. Failure to implement the right of persons with disabilities to an adequate standard of living for themselves and their families is contrary to the objectives of the Convention. To reach an adequate standard of living comparable to others, persons with disabilities typically have additional expenses. States parties therefore have the obligation to implement effective measures to enable persons with disabilities to cover the additional expenses linked to disability.¹⁷ The Committee further notes that the European Court of Justice has found that the principle of equal treatment as regards employment and occupation is not limited to persons who themselves have a disability and its conclusion that, in situations in which employers treat employees who are not themselves disabled less favourably than other employees are, have been or would be treated in comparable situations, and it is established that the less favourable treatment of those employees is based on the disability of their children, whose care is provided primarily by those employees, such treatment is contrary to the prohibition of direct discrimination.¹⁸ The Committee further notes that the European Court of Human Rights found that the discriminatory treatment of an applicant on account of the disability of his child was a form of disability-based discrimination covered by article 14 of the European Convention on Human Rights.¹⁹

7.10 In the present situation, the Committee notes the author's unrefuted argument that, due to the revocation of her right to telecommute, she was no longer in a position to continue her employment, which led her to lose her income. It further notes her argument that, as her daughter and partner require continuous care, telecommuting is a necessary requirement for her to be able to sustain employment and at the same time care for her family members in order to avoid institutionalization. It notes her argument that the fact that she is not able to access employment in the labour market due to her role as a family caregiver amounts to discrimination by association within the meaning of article 5 of the Convention. The Committee further notes that the State party has not provided any information on any form of support measures, assistance or social protection provided to the family in their situation. The Committee therefore finds that the lack of social protection, assistance with disability-related expenses, adequate training, counselling, financial assistance and respite care provided by the State party's authorities amounts to a violation of the rights of the author and her family under article 28, read in conjunction with article 5, of the Convention.

C. Conclusion and recommendations

8. The Committee, acting under article 5 of the Optional Protocol, is of the view that the State party has failed to fulfil its obligations under articles 19, 23 and 28 (2) (c) read in conjunction with article 5 of the Convention, for the author's daughter and partner, as well

¹⁵ General comment No. 6 (2018), para. 17.

¹⁶ *Ibid.*, para. 20.

¹⁷ *Ibid.*, para. 68.

¹⁸ European Court of Justice, *S. Coleman v. Attridge Law and Steve Law*, ECLI:EU:C:2008:415, 17 July 2008, paras. 38, 50 and 56.

¹⁹ European Court of Human Rights, *Guberina v. Croatia*, application No. 23682/13, Judgment, 22 March 2016, paras. 76–79.

as its obligations under article 28 (2) (c), read in conjunction with article 5, for the author herself. The Committee therefore makes the following recommendations to the State party:

(a) Concerning the author, her daughter and partner, the State party is under an obligation:

(i) To afford them adequate compensation, including for any legal costs incurred in filing the present communication;

(ii) To take appropriate measures to ensure that the author's family has access to adequate individualized support services, including respite care services, financial support, counselling services, social support and other adequate support options, in order to ensure their rights under articles 19, 23 and 28 (2) (c) of the Convention;

(b) In general, the State party is under an obligation to take measures to prevent similar violations in the future. In that regard, the Committee requires the State party:

(i) To ensure, through amending its domestic legislation as necessary, that social protection programmes meet the requirements of the diverse range of persons with disabilities on an equal basis with others;²⁰

(ii) To inform persons with disabilities about their right to live independently and be included in the community in ways that they can understand and provide empowerment training with the aim of supporting persons with disabilities to learn how to enforce their rights;²¹

(iii) To implement safeguards to retain the right to autonomous independent living across all regions, and redirect resources from institutionalization to community-based services and increase budget support to enable persons with disabilities to live independently and have equal access to services, including personal assistance and support for family caregivers, where applicable.

9. In accordance with article 5 of the Optional Protocol and rule 75 of the Committee's rules of procedure, the State party should submit to the Committee, within six months, a written response, including information on any action taken in the light of the present Views and recommendations of the Committee. The State party is also requested to publish the Committee's Views, have them translated into the official language of the State party and to circulate them widely, in accessible formats, in order to reach all sectors of the population.

²⁰ General comment No. 5 (2017), para. 97 (c).

²¹ *Ibid.*, para. 97 (f).