



Observatório da Deficiência
e Direitos Humanos

Disability and Human Rights Observatory

**ALTERNATIVE REPORT ON THE TENTH PERIODIC REPORT
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DISCRIMINATION AGAINST WOMEN**

**SUBMISSION PREPARED BY THE DISABILITY AND HUMAN
RIGHTS OBSERVATORY (ODDH)**

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A. Introduction

This report was developed by the ODDH team and its Advisory Board, which includes 20 disability organizations, representing different areas of impairment, three universities and 1 research centre, as well as researchers dedicated to disability studies.

The Disability and Human Rights Observatory (ODDH) was created in 2013 at the Instituto Superior de Ciências Sociais e Políticas of the University of Lisbon (ISCSP-ULisboa) with the mission of monitoring the implementation of disability policies in Portugal and Portuguese-speaking countries and to promote participatory processes of monitoring and the development of the human rights of persons with disabilities.

The Observatory brings together disability researchers, disability organisations and experts in the field of disability and human rights, and operates around four axes - Information, Training, Research and Social Intervention/Policy Advice. Developing active partnerships with national and international disability organisations and networks, the ODDH publishes a trimester newsletter for electronic distribution, as well as research reports with indicators on disability and human rights. More information on the ODDH is available at <http://oddh.iscsp.ulisboa.pt/index.php/en/>.

B. Critical analysis of the situation of women and girls with disabilities

1. Legislative and policy framework

1. Over the last decades, Portugal has made important progress in the adoption of legislative and policy frameworks that protect and advance the rights of persons with disabilities, including the rights of girls and women. New measures recently introduced (also presented in the report submitted by the Portuguese State) encompass the Inclusive Education legislation, several measures to promote the employability of persons with disabilities, including quota schemes for the public and the private sector, a new Social Benefit for Inclusion, a scheme to support Independent Living, the new Supported Adult Regime and the recently introduced Statute of the Caregiver. Moreover, the rights and special needs of girls and women with disabilities are recognised in both the National Strategy for Equality and Non-Discrimination 2018-2030 “*Portugal + Igual*” (ENIND) the which establishes intersectionality as one of its pillars, and the National Strategy for the Inclusion of Persons with Disabilities 2021-2025 (ENIPD).
2. Despite these positive changes at the legal and policy level, girls and women with disabilities continue to be disadvantaged in several areas in relation not just to persons without disabilities but also in relation to boys and men with disabilities as they experience multiple discrimination based on both disability and gender.

2. Education

3. In Portugal, since the Legislation for Inclusive Education was approved, through Decree-Law No. 54/2018 (recently amended by Law No. 116/2019), the official statistical data on the situation of students with disabilities attending compulsory education is no longer available, meaning there is no available data since the school year 2017/18. Although the Portuguese legislation on inclusive education is considered quite advanced, even at an international level (UNESCO, 2020⁶) — mostly for recognising the right of all children to attend regular schools — without available statistical information it is not possible to assess whether the progress in the legislative framework is equally impacting girls and boys with disabilities.
4. Nevertheless, in the school year 2017/18, a trend already noticed in previous years was repeated: a wide discrepancy between the proportion of girls and boys with disabilities

⁶ UNESCO. (2020). *Global Education Monitoring Report 2020: Inclusion and education: All means all*. UNESCO. <http://bit.ly/2020gemreport>

attending compulsory education in regular public and private schools: of all students with disabilities registered, only 38% were girls and 62% were boys (Pinto & Pinto, 2018⁷).

5. This underrepresentation of girls with disabilities is likely to be the consequence of the underdiagnosis of certain impairments (e.g., autism and intellectual disability) among the female school population. Due to gender norms and stereotypes, girls are often more able to mask their symptoms and teachers tend to be less concerned about girls' behaviours in the classroom (usually quieter) than boys' (usually more disruptive), as research elsewhere has already suggested (e.g., Hiller et al., 2014⁸; 2016⁹; Jamison et al., 2017¹⁰; Mandy et al., 2012¹¹; Quinn & Wagner, 2015¹²; Quinn & Madhoo, 2014¹³, cit. by Pinto & Pinto, 2017¹⁴). However, the lack of a proper diagnosis hampers girls with disabilities to get the support they need, thus putting them at greater risk for school unsuccess. This seems to be happening in Portuguese schools, as the wide discrepancy in the numbers of girls and boys labelled as having 'special needs' (and thus getting special support) is showing.

3. Employment

6. Despite the measures that the government has introduced to improve the employability of persons with disabilities, over the last 10 years, between 2011 and 2021, the registered unemployment¹⁵ in the population with disabilities, in mainland Portugal, increased by 30,5%, with this growth being much more accentuated in women (+63,1%), than in men with disabilities (+9,8%). In other words, even before the pandemic, women with disabilities registered as unemployed had already a greater difficulty accessing the labour market than men with disabilities. Moreover, in December 2021, unemployment among the general population as well as among men with disabilities started to register a slight decline (-0,6%), but it continued to increase among women with disabilities. The increase in the percentage of women registered as unemployed is likely due to the combined effect of discrimination based on disability and gender that creates increased barriers for women with disabilities in the labour market, as research elsewhere has concluded (e.g., Brown & Moloney, 2019¹⁶; Moodley & Graham, 2015¹⁷ cit. by Pinto et al., 2022¹⁸).

4. Violence against women

7. Although there are no official statistics on violence against girls and women with disabilities in Portugal, research has shown that they are at greater risk than boys and men. Indeed, a recent study (Fontes et al., 2021¹⁹) conducted a media analysis of print

⁷ Pinto, P. C., & Pinto, T. J. (2018). *Pessoas com Deficiência em Portugal: Indicadores de Direitos Humanos 2018*. ODDH/ISCSP-ULisboa. <http://oddh.iscsp.ulisboa.pt/index.php/en/2013-04-24-13-36-12/publications-of-oddh-researchers/item/390-report-oddh-2018>

⁸ Hiller, R.M., Young, R.L., & Weber, N. (2014). Sex differences in autism spectrum disorder based on DSM-5 criteria: evidence from clinician and teacher reporting. *Journal of Abnormal Child Psychology*, 42(8), 1381-1393. <https://doi.org/10.1007/s10802-014-9881-x>

⁹ Hiller, R.M., Young, R.L., & Weber, N. (2016). Sex differences in pre-diagnosis concerns for children later diagnosed with autism spectrum disorder. *Autism*, 20(1), 75-84. <https://doi.org/10.1177/1362361314568899>

¹⁰ Jamison, R., Bishop, S., Huerta, M., & Halladay, A. (2017). The clinician perspective on sex differences in autism spectrum disorders. *Autism*, 21(6), 772-784. <https://doi.org/10.1177/1362361316681481>

¹¹ Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex differences in autism spectrum disorder: evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders*, 42(7), 1304-1313. <https://doi.org/10.1007/s10803-011-1356-0>

¹² Quinn, J. M., & Wagner, R. K. (2015). Gender Differences in Reading Impairment and in the Identification of Impaired Readers: Results From a Large-Scale Study of At-Risk Readers. *Journal of Learning Disabilities*, 48(4), 433-445. <https://doi.org/10.1177/0022219413508323>

¹³ Quinn P.O., Madhoo, M. (2014). A Review of Attention-Deficit/Hyperactivity Disorder in Women and Girls: Uncovering This Hidden Diagnosis. *The Primary Care Companion to CNS Disorders*, 16(3). <https://doi.org/10.1177/1087054719841133>

¹⁴ Pinto, P. C., & Pinto, T. J. (2018). *Pessoas com Deficiência em Portugal: Indicadores de Direitos Humanos 2017*. ODDH/ISCSP-ULisboa. <http://oddh.iscsp.ulisboa.pt/index.php/en/2013-04-24-13-36-12/publications-of-oddh-researchers/item/352-report-oddh-2017>

¹⁵ Registered unemployment includes all the persons who register with the National Institute for Employment and Vocational Training as unemployed and looking for a job. Since all programmes and services offered by this Institute require a registration, the increase in the percentage of women and men with disabilities registered as unemployed may also reflect a greater demand, on their part, for the services provided by this Institute.

¹⁶ Brown, R. L. & Moloney, M. E. (2019). Intersectionality, work and well-being: The effects of gender and disability. *Gender & Society*, 33(1), 94-122. <https://doi.org/10.1177/0891243218800636>

¹⁷ Moodley, J., & Graham, L. (2015). The importance of intersectionality in disability and gender studies. *Agenda*, 29(2), 24-33. <https://doi.org/10.1080/10130950.2015.1041802>

¹⁸ Pinto, P. C., Neca, P., & Bento, S. (2022). *Pessoas com Deficiência em Portugal: Indicadores de Direitos Humanos 2021*. ODDH/ISCSP-ULisboa. <http://oddh.iscsp.ulisboa.pt/index.php/en/2013-04-24-13-36-12/publications-of-oddh-researchers/item/561-report-oddh-2021>

¹⁹ Fontes, F. (2018, July, 5-6). Disability and violence: multiple oppressions, intersectional readings. In *Transforming practices and knowledge through the lens of disability: experiences, transmissions, training, organizations*. VII Annual Conference of ALTER - European Society for Disability Research, Lille – France.

news on crimes committed against persons with disabilities between 2002 and 2012 and concluded that in the 274 news collected, 70% of the victims were women. According to the same study, 32% of the crimes against persons with disabilities reported in the newspapers analysed involved rape, 18% sexual abuse, and 18% physical assault. Furthermore, a gender analysis by type of crime revealed that disabled women were overrepresented in rape, sexual abuse, rape attempt and physical assault, whereas 90 % of the perpetrators were males. Other perpetrators included family members (32%), strangers (23%), staff from disability-service providers (12%), members of the community (10%), and neighbours (8%). Finally, the study concluded that 52% of that violence occurred just once, while in 48% of the cases it was repeated over time. These data demonstrate that gender violence against persons with disabilities in Portugal is a reality and affects predominantly girls and women with disabilities.

8. It is also important to note that the Committee on the Rights of Persons with Disabilities in its General Comment No. 1 on Article 12 of the CRPD: Equal recognition before the law (2014), states that “women with disabilities are subjected to high rates of forced sterilization and are often denied control of their reproductive health and decision-making, the assumption being that they are not capable of consenting to sex.” Women with disabilities are particularly vulnerable to forced sterilizations performed under the auspices of legitimate medical care or the consent of others in their name (Public Health Program, 2011²⁰). Forced sterilisation constitutes an act of violence (FIGO²¹, 2011), which in many countries is debated and justified by professionals and family members and carers as being in the best interests of women and girls with disabilities (Davaki et al., 2013²²).
9. Although Portugal states a strong commitment to fight “all forms of violence against women” (para. 35 of the State report), the State report that has been submitted to the CEDAW committee makes no mention of the thematic of forced sterilisation of women with disabilities.
10. Certainly, the Portuguese Doctors' Code of Ethics states that "methods of irreversible sterilization, tubal ligation and vasectomy can only be performed at the request of the patient and with their express and explicit consent, after detailed explanation about the risks and the irreversibility of such methods." These procedures "should only be performed on minors or persons with disabilities after a duly substantiated request (...) The consent of minors or patients with cognitive alterations that make them incapable (...) of giving their consent, must be requested from their legal representative, [being] the physician to consider, in each case, the need to request to the court the judicial supply of the patient's consent".
11. Nevertheless, while there are no official statistics on forced sterilisations performed in Portugal on women with disabilities, the already mentioned study by Fontes et al. (2021), also included 15 focus groups across the country with staff working in NGOs providing services to persons with disabilities and disability activists. During the discussions in these focus groups, it was often reported that “another form of violence committed against disabled women with cognitive impairments is forced sterilization (Laparoscopic tubal ligation)”; the authors conclude that this form of violence continues to take place in the country, regardless the socioeconomic and/or cultural background of the girls and women with disabilities. This situation compounds the disenfranchisement and great vulnerability for the violation of fundamental human rights that girls and women with disabilities face in Portugal.
12. On a more positive note, we acknowledge the creation of the first shelter for women with disabilities, victims of domestic violence in Portugal in 2018, and the first shelter for women with mental illness, victims of domestic violence in 2019 (para. 74 of the State report). However, given the greater exposure to violence that girls and women with

²⁰ Public Health Program. (2011). *Sterilization of Women and Girls with Disabilities*. Briefing Paper. https://www.opensocietyfoundations.org/publications/sterilization-women-and-girls-disabilities-0#publications_download

²¹ International Federation of Gynaecology and Obstetrics (FIGO).

²² Davaki, K., Marzo, C., Narminio, E., & Arvanitidou, M. (2013). *Discrimination Generated by the Intersection of Gender and Disability*. European Parliament, Directorate-General for Internal Policies of the Union, Publications Office. <https://data.europa.eu/doi/10.2861/23765>

disabilities face, there is a need for more measures to increase awareness about the multiple discrimination they experience, empower them, increase their access to justice and protect and promote their sexual and reproductive rights.

5. Social protection and living conditions

13. In the area of social protection, we acknowledge the introduction by the Portuguese government in 2017 of the Social Benefit for Inclusion (PSI)²³ (para. 15 of the State report), as a measure to mitigate the risk of poverty or social exclusion of people with disabilities. According to data provided by the Social Security Institute, there has been an exponential growth of beneficiaries since the entry into force of this benefit (2017; N = 21 307) in the order of 438% (2020; N = 114 726) (Pinto et. al., 2022). Unfortunately, the data provided by the Social Security Institute does not disaggregate PSI beneficiaries by sex, which prevents a gender analysis of this indicator.
14. Nevertheless, Eurostat data²⁴ shows that, in Portugal, in 2020, the households of women with disabilities were the group facing the greatest risk of poverty or social exclusion, (26,8% vs. 24,6% for households of men with disabilities). In addition, in 2020, the gap in this indicator was 10.4 p.p. between the households of women with and without disabilities (26,8% vs. 16,4%) and only 7.8 p.p. between the households of men with and without disabilities (24,6% vs. 16,8%). In other words, the disparity remained almost the same compared to 2016, in the case of women (it was 10.2 p.p. in that year) but decreased in the case of men with and without disabilities (from 10.7 to 7.8 p.p.) (Pinto et. al., 2022). This again suggests that the vulnerability of women with disabilities and their households to poverty is more persistent than that of men with disabilities.
15. Moreover, annual data on pensions and social benefits²⁵ reveals that, in 2020, in Portugal, as in previous years, the number of male beneficiaries in all benefits related to disability, dependence and incapacity, is always greater than the number of women, and that the disparity is even greater in the case of family benefits, such as the Special Education Allowance (+28,2%), the Complement to the Family Benefit (+23,6%), and the Third-person Assistance Allowance (+16,4%) (Pinto et. al., 2022).

6. Informal caregivers of persons with disabilities

16. The ODDH acknowledges the introduction of the Status of the Informal Caregiver in Portugal, through Law 100/2019, of September 6, regulating the rights and duties of the carer and cared person, and defining support measures. This is a must needed legislation, but it remains insufficient to address current needs, as it excludes from supports and benefits caregivers who combine the provision of care with paid work.
17. In Portugal, most of the care work provided within the household is women's work, including care for persons with disabilities. This is done within a context where most women also work full-time in the labour market, as Portugal is one of the countries in Europe with the highest rates of female employability (Torres et al., 2018²⁶). During the COVID-19 pandemic lockdowns, care services for persons with disabilities were suspended or reduced and the burden of care was transferred even more strongly to women in the families. A study developed by the ODDH in 2020²⁷, regarding the impact of the COVID-19 pandemic on persons with disabilities and their caregivers, found that

²³ Decree-Law No. 126-A/2017: Introduced in October 2017, this benefit is granted to people with disabilities (with a degree of incapacity equal to or higher than 60%) and comprises three components: the Basic Component, the Complement and the Surcharge. In the first phase, it was only intended for the adult population and, as of October 2019, it was extended to children and young people under the age of eighteen.

²⁴ Eurostat. (2022). *People at risk of poverty or social exclusion by level of activity limitation, sex and age*.

https://ec.europa.eu/eurostat/databrowser/view/hlth_dpe010/default/table?lang=en.

²⁵ GEP-MTSS. (2021). *Pensões - Dados Anuais [2001 a 2020], Prestações Familiares - Dados Anuais [2005 a 2020] & Prestação Social para a Inclusão - Dados Anuais [2017 a 2020]*. <https://www.seg-social.pt/estatisticas>.

²⁶ Torres, A. (Coord), Pinto, P. C., Costa, D., Coelho, B., Maciel, D., Reigadinha, T., & Theodoro, E. (2018). *Igualdade de género ao longo da vida: Portugal no contexto europeu. Resumos da Fundação*. Fundação Francisco Manuel dos Santos; CIEG/ISCSP-ULisboa.

²⁷ Pinto, P. C., & Neca, P. (2020). *Deficiência e COVID-19 em Portugal: Resultados de um estudo realizado com pessoas com deficiência e cuidadoras/es*. ODDH/ISCSP-ULisboa. <http://oddh.iscsp.ulisboa.pt/index.php/en/2013-04-24-13-36-12/publications-of-oddh-researchers/item/490-relatorio-oddh-2020>

women were overrepresented among family members providing care (n = 88; 83% were female and only 17% were male). The same study indicated that caregivers were experiencing high levels of exhaustion and burnout, due to the difficult situation of juggling care work with their professional responsibilities. One woman said: *“I was able to continue my professional activity from home, however, I had to work almost every night to make up for the time I was taking care of my son during the day.”* (Female carer of a 10-year-old child with a disability); And another reported: *“My son has a disability with 80% of incapacity, so he needs constant surveillance. I was forced to ask for a continuous work shift and his older sister asked to work only night shifts, so we ensured his care between the two of us. One stayed with him during the day, and the other during the night.”* (Female carer of a 14-year-old child with a disability). These are just a few examples of situations that the Law does not adequately protect.

18. While we recognise that female family members still play a crucial role in supporting persons with disabilities in Portugal, often at great personal cost, we highlight that this is the outcome of a familialist and weak welfare state that relies on families to provide essential care. In this regard, we stress the need for greater public investment in the provision of Personal Assistants to all persons with disabilities, in accordance with the Independent Living model that is advanced by a true human rights approach to disability.

7. Statistics and data collection

19. Disaggregated data on girls and boys, women and men with disabilities are not systematically collected in the most important surveys, administrative sources and national statistics, which makes it difficult to compare the situation of persons with disabilities with the general population or to highlight the specific gender disparities that persist within the population with disabilities. Furthermore, specific data on persons with disabilities are also missing – the first official data collection on persons with disabilities – the National Survey on Impairment, Disability and Disadvantage – was conducted in 1995, and has not been repeated since then. It is urgent to address this gap.

C. Recommendations

To address the problems, insufficiencies and gaps described above we propose:

8. In relation to Education

20. To increase attention to the educational needs of girls with disabilities and provide them with a timely assessment and adequate support;
21. To increase the provision of training on disability, gender and inclusive education in the continuous training of teachers and non-teaching staff, namely regarding assessment and intervention strategies;
22. To create inclusive schools these topics should receive high priority.

9. In relation to Employment

22. To enforce the employment quotas for persons with disabilities in the public and private sector;
23. To improve the monitoring and enforcement mechanisms concerning the prohibition of discriminatory practices on the grounds of gender and disability in the workplace;
24. To reinforce complaint and protection mechanisms regarding work-related harassment and violence and to raise awareness about gender and disability issues among employee support structures (e.g., Ombudsman, unions, workers' committees);

25. To raise employers' awareness about gender and disability issues and to promote corporate social responsibility concerning the employment of women with disabilities.

10. In relation to Violence against women with disabilities

26. To develop policies, programmes and support services related to the promotion of the sexual and reproductive rights of women with disabilities;
27. To strengthen research and intervention aimed at combatting violence against girls and women with disabilities, building their capacity and empowerment and facilitating their access to justice;
28. To promote the training of sexual and reproductive health practitioners on disability-related issues.

11. In relation to Social protection and living conditions and the role of informal caregivers

29. To raise the amount of disability-related cash benefits, and to review the eligibility criteria to access them in order to ensure an adequate standard of living for girls and women with disabilities and their households;
30. To amend the Status of the Informal Caregiver so that it covers caregivers who combine care with paid work;
31. To support female informal caregivers of persons with disabilities, so that they can play their role safely and respect the human rights of the persons with disabilities being cared for;
32. To create a national scheme to support independent living, replacing the current pilot projects and providing persons with disabilities with the number of hours of personal assistance according to their needs, while liberating female family members from their (often imposed) caregiver role.

12. In relation to Statistics and data collection

33. To improve the systematic gathering of statistical data on persons with disabilities, disaggregated by sex;
34. To conduct a nationwide survey on disability, collecting detailed data on the living conditions of persons with disabilities, disaggregated by sex. All of this should be done with the active participation of women with disabilities.