



# Supporting Mothers with Disabilities: A Call for Enhanced Care and Resources

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Report by *Make Mothers Matter*

info@makemothersmatter.org  
[www.makemothersmatter.org](http://www.makemothersmatter.org)

## Background

The European Economic and Social Committee has produced data highlighting that of the people living with a disability within the European Union, nearly 40 million are women and girls, accounting for 16% of the EU's total population<sup>1</sup>. While there is significant lack of research regarding disability in general, there is a concerning gap in the literature that examines the specific experiences and requirements of mothers with disabilities as well as mothers caring for children with disabilities. The latter can be defined by the term 'disability by proxy' which refers to the structural and societal barriers mothers experience as primary caregivers to children with disabilities. This lack of focus results in widespread misunderstanding of the unique challenges these women face, this includes as carers, access to healthcare, mental health and day-to-day discrimination and bias.

At MMM we recognise the intersectionality of disability, creating compounded barriers for women, particularly when faced with motherhood. These women not only face the everyday demands of raising children, but also the added complexities of navigating their own needs in a world that is often physically, socially and structurally inaccessible. Instead of a social system that accommodates these needs, these women often face judgement and discouragement in becoming mothers<sup>2</sup>. In addition to this, the time-consuming nature of care work often results in little time for mothers to prioritise their own healthcare needs<sup>3</sup>. This paper discusses the experiences of both mothers with disabilities and mothers of children with disabilities. However, the primary focus is on mothers with disabilities, as findings from the EU Erasmus+ funded project ASSIST revealed that their challenges are often more severe and remain underrepresented in literature.

However, when healthcare is sought there are barriers in access and often discrimination faced. This includes inadequately equipped healthcare facilities, insufficient support for women on their pregnancy journey including before, during and after, as well as social attitudes undermining their parenting abilities. By failing to recognise the specific needs of all mothers, whether living with disabilities or caring for children with disabilities, mothers continue to face barriers in access to essential resources and support in their roles as caregivers. This is driven and compounded by systemic discrimination towards mothers with disabilities within and outside of healthcare. This stigma that mothers face not only affects their access to appropriate healthcare services but also results in a lack of understanding from healthcare providers. As a result, mothers with disabilities and mothers caring for children with disabilities are often forced to navigate a healthcare system that is ill-equipped to meet their needs, further isolating them and exacerbating the challenges they face. Similar forms of discrimination in the employment setting further reinforces 'disability by proxy' for mothers who care for children with disabilities, limiting employment opportunities and career

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<sup>1</sup> *Europe must do more to protect women with disabilities* (2018).  
<https://www.eesc.europa.eu/en/news-media/news/europe-must-do-more-protect-women-disabilities>.

<sup>2</sup> Carotta, C. (2024) *Mother Matters - motherhood for women with disabilities*.  
<https://epale.ec.europa.eu/en/blog/mother-matters-motherhood-women-disabilities>.

<sup>3</sup> Includovate (2024) *Beyond Boundaries: Unpaid Care Work and Its Impact on Women, Including Those with Disabilities*.  
<https://www.includovate.com/beyond-boundaries-unpaid-care-work-and-its-impact-on-women-including-those-with-disabilities/>.

development. According to a study of mothers in Norway, mothers of children with disabilities experience substantially lower labour market participation and income, as caregiving responsibilities often require reduced working hours<sup>4</sup>. This situation is often exacerbated by systemic shortcomings, as many mothers described being forced to prioritise care over paid work, resulting in continuous financial stress, concerns about securing their child's future, and difficulty accessing adequate support from welfare, healthcare and educational systems<sup>4</sup>.

These challenges, combined with a persistent lack of research and understanding, create an environment where voices and experiences of mothers with disabilities and mothers caring for children with disabilities are marginalised. This paper aims to shed light on the issues of maternal mental health, unpaid care work, access to healthcare and discrimination. We advocate for greater attention to the intersection of disability and motherhood, call for policies that are inclusive and support empowering women with disabilities in the EU.

## Key Challenges

### Maternal Mental Health

The societal stigma and caregiving challenges that mothers with disabilities face can often result in significant mental health challenges. Many mothers with disabilities report heightened stress, anxiety and depression due to the lack of support during pregnancy, childbirth and motherhood. These mental health issues are often overlooked as healthcare providers may lack awareness of the intersectional challenges faced by these mothers, such as the compounded stress of balancing caregiving with their own healthcare needs. Similarly, literature has shown that parents caring for children with disabilities report higher stress levels, highlighting the mental health impact of caregiving responsibilities<sup>5</sup>.

### Recommendations

- Healthcare systems should make mental health services for mothers with disabilities more accessible with provisions of tailored psychological support for mothers.
- Promote an integration of disability awareness into medical curricula and healthcare training.
- Promote a more inclusive healthcare environment that addresses not just the physical but also the emotional needs of mothers with disabilities.

### Unpaid care work

Unpaid care work is disproportionately carried out by women, including those with disabilities, and is often invisible and undervalued. For mothers who experience 'disability by proxy' due to their

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<sup>4</sup> Østerud, K. L., Skjønberg, E. E., & Albertini Früh, E. (2024). "My child is my job now" – Care, work and careers of mothers with disabled children in the Norwegian welfare state. <https://www.sciencedirect.com/science/article/pii/S0277953624005501>

<sup>5</sup> Scheibner, C., Scheibner, M., Frauke Hornemann, Arélin, M., Yvonne Doris Hennig, Kiep, H., Wurst, U., Merkschlager, A., & Gburek-Augustat, J. (2023). Parenting stress in families of children with disabilities: Impact of type of disability and assessment of attending paediatricians. <https://doi.org/10.1111/cch.13193>

caregiving responsibilities, these demands often limit their ability to find employment. This unpaid care and domestic work can be physically demanding and mentally taxing, especially for women with disabilities. There is additional hardship of balancing caregiving responsibilities with their own healthcare needs, leading to increased stress and lack of time for self-care. The societal stigma attached to caregiving roles, coupled with significant discrimination related to disability further exacerbates these challenges.

### Recommendations

- Focus on providing and expanding legal and social protections for caregivers.
- Improvement on access to caregiving resources with a recognition of the varying needs of mothers with disabilities.
- Recognise the role of advocacy caregivers in promoting the recognition of mothers with disabilities.
- Development of an inclusive infrastructure that supports both caregivers and those they care for.
- Raising awareness of the value of unpaid care work and its impact on women with disabilities.

### Access to healthcare services

Mothers with disabilities often face numerous barriers to accessing quality healthcare, including physical, informational and attitudinal obstacles. Inaccessible healthcare facilities and the absence of adaptive equipment further isolates mothers with disabilities from the healthcare system. In addition, the lack of disability awareness among healthcare providers creates significant challenges for these women including biased treatment or inadequate care. This characterises healthcare facilities as places of neglect and lacking safety for these women.

### Recommendations

- A striving effort towards eliminating attitudinal barriers and increasing disability awareness among healthcare professionals.
- Ensuring that healthcare facilities are physically accessible and have the provisions necessary for adaptive equipment.
- Training healthcare staff in disability-inclusive care.
- Enhance the availability of assistive technologies that improve communication and mobility for mothers with disabilities.
- Focus on creating safe spaces for women with disabilities in healthcare settings with a focus on respect, privacy and comfort.

### Discrimination and Bias

Discrimination remains a significant issue for mothers with disabilities and is the main driver of many of the inequities they face, particularly in the healthcare system. Negative stereotypes and misconceptions regarding their ability to care for their children often leads to discriminatory

practices. The intersectional discrimination regarding gender and disability can have devastating effects on the well-being of both mothers and their children. In healthcare settings, biases can lead to a lack of respectful care, where women with disabilities are not treated as autonomous individuals capable of making informed decisions about their reproductive health. Similar biases operate in employment settings, reinforcing barriers to an equitable hiring process.

### Recommendations

- Addressing discrimination with an intersectional approach which accounts for multiple forms of biases and marginalisation.
- Foster an inclusive care approach in training professionals.
- Promote legal protections that safeguard the reproductive rights and parenting rights of women with disabilities.
- Recognise the vitality of informed consent for women with disability in all healthcare decisions, including those regarding their reproductive rights.
- Advocate for the inclusion of women with disabilities in society with a particular focus on underrepresented groups.
- Ensure the voices of people with disabilities and their families are promoted in policy making and decisions regarding their rights with a particular focus on existing advocacy groups and community organisations.
- Comply with international legal frameworks such as the UN Convention on the Rights of Persons with Disability<sup>6</sup> with reference to the reproductive rights for women with disability.
- Ensuring inclusion of mothers with disabilities using the Union of Equality Strategies for the Rights of Persons with Disabilities 2021-2030<sup>7</sup>.

### Case Study - Sweden<sup>8</sup>

Sweden's LSS law (The Act on Support and Service for Persons with Certain Functional Impairments) functions under the Social Services Act (2001) and protects mothers with disabilities, ensuring tailored support for families. While there has been criticism on the accessibility of these services, the framework provides a good example of recognising and accounting for the unique challenges of mothers with disabilities. The law applies to people with a wide range of physical, intellectual, or

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<sup>6</sup> *UN Convention on the Rights of Persons with Disabilities: Respect for home and the family (Article 23 1b)* (2006) United Nations. United Nations Human Rights Office of the High Commissioner. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities> (Accessed: January 21, 2025).

<sup>7</sup> *Union of equality: Strategy for the rights of persons with disabilities 2021-2030*. [https://employment-social-affairs.ec.europa.eu/policies-and-activities/social-protection-social-inclusion/persons-disabilities/union-equality-strategy-rights-persons-disabilities-2021-2030\\_en](https://employment-social-affairs.ec.europa.eu/policies-and-activities/social-protection-social-inclusion/persons-disabilities/union-equality-strategy-rights-persons-disabilities-2021-2030_en).

<sup>8</sup> Informationsenheten (2014) *LSS –the Law regulating Support and Service to Persons with Certain Functional Disabilities– in brief*. [https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/12/Sweden\\_Act-concerning-Support-and-Service-to-Persons-with-Certain-Functional-Disabilities-LSS.pdf](https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/12/Sweden_Act-concerning-Support-and-Service-to-Persons-with-Certain-Functional-Disabilities-LSS.pdf).

mental disabilities that impact their ability to manage daily activities. It guarantees personal assistance and adapts plans based on the person's specific needs such as additional care in the house, respite when needed to prioritise self-care and adaptive equipment that may be deemed necessary. The LSS law is founded on principles of self-determination and equality, allowing individuals to choose and customise the services they receive based on their needs and preferences. This largely includes support of mothers with disabilities in their care for their families, ensuring women facing these obstacles are heard and the necessary adaptations are made.

Sweden has demonstrated a recognition of the challenges that mothers with disabilities face day-to-day and this law indicates necessary steps forwards in mitigating these obstacles, with an aim to take the added pressure off daily tasks and caring responsibilities these women often face. This is a key example in adaptive change which we promote in our recommendations below.

## Concluding Remarks

The intersection of disability and motherhood presents a unique set of challenges that are too often overlooked and stigmatised. Mothers with disabilities face compounded barriers in their role as caregivers, from physical and social inaccessibility to systemic discrimination. In addition to this the insufficient healthcare support creates barriers in accessing necessary physical and mental health support. These challenges not only impact their day-to-day caregiving responsibilities but also their ability to care for themselves. Beyond this, mothers of children with disabilities experience 'disability by proxy,' whereby caregiving responsibilities expose them to discrimination and economic disadvantage. It is imperative that healthcare systems, policies and society recognise and adapt to the specific needs of mothers with disabilities and mothers affected by 'disability by proxy,' providing targeted support that empowers them in their everyday activities. Moving forward, it is necessary to advocate for inclusive change and legal protections to eliminate the barriers mothers with disabilities and mothers caring for children with disabilities face, ensuring they are provided with the care, respect and resources they need. Only through this comprehensive support can we begin to create an equitable environment where mothers with disabilities and mothers caring for children with disabilities can thrive, both as parents and as individuals.