Autism-Europe's submission to the call for inputs on Care and support for children with disabilities within the family environment and its gendered dimensions

Autism-Europe, is an international association representing autistic people and their families. With 90 member autism organisations from 40 European countries including 26 Member States of the European Union.

Autism-Europe coordinated the collection of data through a detailed online survey conducted among individuals from our member organisations across European Union member states. The responses provide a snapshot of the current realities experienced by families supporting autistic children and adults. This report is also informed by insights drawn form the national long-term care reports recently submitted by EU member states as required following the adoption of the Council Recommendation on affordable high-quality long-term care.[1] In this context these reports provide information in relation to how national governments address the issue of informal care and whether they have considered the council recommendation's guidance on informal carers[2] which provides essential context for the lived experiences shared through the survey. The analysis is framed within the international human rights framework, particularly drawing on the Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Rights of the Child (CRC), and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

Demographic Overview

The survey received 159 responses. The demographic profile of the respondents revealed that the majority of caregivers were aged between 35 and 54 years. This age range typically corresponds to the period of maximum economic productivity and familial responsibility, indicating a significant intersection of caregiving with professional and personal obligations. Most families reported caring for a single autistic child or adult dependent, although a notable minority indicated caring for two or more. These caregiving roles were overwhelmingly assumed by mothers, a finding consistent with the policy brief by Eurocarers[3] published at the beginning of this year and a report by COFACE[4] , which both describe a persistent gender imbalance in informal care provision across Europe. This gendered distribution of care echoes concerns raised under CEDAW regarding the unequal burden of unpaid care work on women.

Furthermore, nearly all families reported that the autistic person in their care held officially recognised disability status in their respective countries or regions. The

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[1] https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.C_.2022.476.01.0001.01.ENG

[2] Ibid, para 9, 10, 20.

[3] https://eurocarers.org/new-policy-brief-available-national-reports-on-the-implementation-of-the-council-recommendation-on-access-to-high-quality-long-term-care-policy-takeaways-for-informal-carers/

[4] https://coface-eu.org/study-on-the-challenges-and-needs-of-family-carers-in-europe/

respondents came from a diverse array of European countries, with strong representation from western and southern Europe. Regarding gender distribution, the survey respondents were 83% female, further reinforcing the gendered nature of caregiving responsibilities. These findings highlight the need for states to comply with their obligations under Article 5 of CEDAW to recognise and address the intersectional discrimination faced by mothers in their caregiving roles within the family.

Family Support and Challenges

Mothers emerged as the primary caregivers in most surveyed households. Out of the 159 respondents 108 families identified the mother as the primary caregiver while only 5 identified the father as the main caregiver. This trend reflects deeply entrenched gender roles in care responsibilities. This finding aligns with COFACE's policy analysis, which illustrates that caregiving continues to be viewed as a familial and often maternal duty rather than a shared societal obligation. This is well cited by academic studies.[5] The sharing of caregiving responsibilities between parents was relatively less common at just 22% among families surveyed, and in many cases, fathers were either minimally involved or absent from daily care routines.

The economic impact of caregiving for families of autistic children and adults was widely reported. Over 85% of families indicated that their household income had been either somewhat or significantly negatively affected by caregiving responsibilities. This was largely due to adjustments in employment, whether this was due to reduced working hours or a complete withdrawal from the workforce. Specifically, 42% of primary caregivers reported having to leave their jobs entirely and 32% were forced to scale back their professional commitments to meet the demands of caregiving. Many mothers in particular reporting that if they managed to remain in the labour market, they were forced to take lower paid roles with less opportunity for growth. A smaller, yet significant, number also indicated that their educational aspirations had been interrupted or abandoned altogether. This data evidences the dual burden of financial instability and lost economic opportunity borne by mainly female caregivers. As was reported in Autism-Europe's alternative report, studies have found that unemployment in families directly affected by autism is up to 20% higher than other families. Further, the cost of raising and caring for an autistic child is estimated to be six times greater than for other children.[6] Without adequate

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[5] Herrero, R., Díaz, A., & Zueco, J. (2024). The Burden and Psychological Distress of Family Caregivers of Individuals with Autism Spectrum Disorder: A Gender Approach. *Journal of Clinical Medicine*, *13*(10), 2861. https://doi.org/10.3390/jcm13102861

[6] Dückert, S., Gewohn, P., König, H. *et al.* Multidimensional Burden on Family Caregivers of Adults with Autism Spectrum Disorder: a Scoping Review. *Rev J Autism Dev Disord* (2023). https://doi.org/10.1007/s40489-023-00414-1

social protections this leaves informal carers and their autistic children or dependents at a high risk of poverty.

The emotional and physical toll of caregiving was another recurring theme. More than 70% of respondents stated that caregiving had negatively impacted their mental and/or physical health, with many describing chronic stress, anxiety, and fatigue. Most narratives pointed to a lack of accessible mental health support for caregivers, compounding the pressure they face. Many families articulated a sense of being left alone to navigate complex systems with minimal support.

Respondent, mother of autistic girl from Latvia *"I often ask myself, where is my time, my needs?"*

Mother of 2 autistic children from Portugal "*When children where little, no nursery would take them, meaning mums life consisted of 24 hour care. This lack of work, income and freedom led me to depression and hostility. The constant blaming myself for their condition was self inflicted and painful."*

Mother of autistic boy from Romania: *"no time to be myself, I don't even remember what it was like before"*

When asked whether female caregivers experience additional challenges compared to male caregivers, a significant majority answered in the affirmative. The reasons provided included unequal societal expectations, reduced access to economic opportunities, and the invisibility of their caregiving contributions in policy and practice. One mother from France spoke to the reality that since the woman is likely already the person with the lower salary it is just expected that she leaves her career to fulfil the unpaid caregiving role.

Mother of autistic child living in Luxembourg: "*As a mother, society asked me to sacrifice my life for my autistic child"*

These reflections echo the findings of Eurocarers' policy brief, which notes the lack of systemic recognition and support for informal carers, particularly women, across EU member states and the Council Recommendations' findings that the bulk of care giving is done by informal care givers, mostly women. The Recommendation goes on to state that providing informal care can negatively affect carers' physical and mental health and well-being and is a significant obstacle to employment, particularly for women. That has an immediate effect on their current income and affects their old-age income due to a reduced accrual of pension rights, which can be even more significant for carers with additional childcare responsibilities.

Female respondents to the survey detail the level of exhaustion they feel from the lack of support they receive in caring for their autistic children. States must address these inequalities in line with CEDAW's implicit call for redistribution of unpaid care work between men and women through its provisions for elimination of gender-based discrimination. Also, via article 11.2(c) which compels countries to provide necessary supporting social services to enable parents to combine family obligations with work responsibilities and participation in public life, in particular by promoting the establishment and development of a network of child-care facilities. The 2019 Recommendation on high-quality early childhood education and care systems adopted by the EU reinforces this need for change.[7] The Recommendation supports Member States in their efforts to improve access to and the quality of early childhood education and care.

Social stigma emerged as another critical issue, with over half of respondents reporting negative experiences due to social perceptions of autism and caregiving. Families described instances of exclusion, misunderstanding, and blame from their communities. This stigma not only isolates families socially but also reinforces structural barriers to accessing support and services. A compounding barrier within the disability movement is apparent for those with complex support needs and their carers. Stigma, even seen within the autism and disability community, is most felt by those who have the highest of support needs. At a recent Autism-Europe conference hosted at the European Parliament a young woman, a sibling of an autistic woman who requires 24-hour support, spoke of the profound isolation she and her family feel within their community and in their attempts to advocate for their autistic family member. This sister who has spent most of her life as an informal carer expressed her frustration with the lack of visibility given to members of the autism community who cannot advocate for themselves. Her feeling was that the overall movement towards autism acceptance/awareness has ignored adults and children like her sister and denied their carers the right to shine a light on their reality. Article 8 of the CRPD obliges States to, inter alia, combat stereotypes and raise awareness throughout society of the rights and dignity of disabled persons. The denial of social inclusion and community participation for disabled persons contravenes Article 19 of the CRPD and undermines the children's right to protection from discrimination as outlined in Article 2 of the CRC. The stigma must be lifted for the whole community, this can only be done with an intersectional approach to campaigns, policy and legislation.

In terms of early intervention, families reported the availability of some services such as early identification and therapy programs. However, the accessibility, affordability, and regional equity of these services varied widely. Many respondents expressed frustration with long waiting lists, bureaucratic barriers, and geographic disparities. These obstacles often rendered support ineffective or inaccessible when it was most urgently needed. Early diagnosis and interventions are critical to autistic children's development. These delays in access to diagnosis leave families in a state of prolonged crisis and compounding difficulties, including unmet educational needs and higher risk of additional disabilities. Autism-Europe has reported on the situation for autistic children during COVID-19 which saw many lose access to essential

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[7] https://www.eumonitor.eu/9353000/1/j9vvik7m1c3gyxp/vkz5624a62zv

services and support networks.[8] This scenario reflects the persistent failure across Europe to guarantee early and appropriate interventions for children with disabilities, contrary to Article 26 of the CRPD and Article 23 of the CRC.

Legal, Policy, and Social Support

The survey responses revealed a patchwork of financial support mechanisms available to family caregivers across Europe. While some countries provide caregiver allowances, pensions, or tax credits, many families reported receiving little to no financial assistance. In contexts where financial support for family carers existed, the application processes were often described as opaque and burdensome. A mother from Czech Republic expressed the precarious nature of obtaining financial support; *"Care allowance from the state is very difficult to obtain a higher level even if your child is severely disabled. Everything depends on how well the medical report from the specialist is written and which 'fairy tale' doctor you happen to encounter."* The lack of comprehensive financial aid undermines the right to social protection under Article 28 of the CRPD and Article 26 of the CRC.

For autism specific social protection laws, only 55 respondents were aware of their existence in their country. A considerable number of respondents indicated that they were unaware of any social protection laws specifically supporting families of autistic children or adult dependents. In countries where such policies exist, implementation gaps and lack of awareness among beneficiaries remain significant challenges. Families consistently called for more transparent, comprehensive, and accessible forms of state support. The absence of effective legal and policy frameworks violates state obligations under Articles 4 of the CRPD, which require appropriate legislative, administrative, and other measures for the implementation of disability rights.

When asked what types of support would most benefit their family, respondents highlighted financial support, respite care, carer leave from work, community services, and better access to therapies and assessments. Psychosocial support, legal protections, and peer networks were also mentioned as essential components of a robust support system yest unavailable or not accessible. However, many families reported difficulties in accessing even basic services. Affordability, long waiting lists, and geographical inaccessibility were among the most common barriers cited.

Eurocarers' analysis of the national long-term care reports affirms these experiences, noting a systemic under-recognition of informal caregivers throughout the EU. The briefing on the national reports identifies a lack of integrated approaches to care, insufficient investment in respite services, and minimal cross-sector collaboration as widespread issues.[9] These systemic failings exacerbate the burdens faced by

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[8] https://www.autismeurope.org/blog/2021/01/22/impact-of-covid-19-on-autistic-people-and-their-families-across-europe/

[9] https://eurocarers.org/new-policy-brief-available-national-reports-on-the-implementation-of-the-council-recommendation-on-access-to-high-quality-long-term-care-policy-takeaways-for-informal-carers/ p 9 (table)

families and reduce their capacity to provide quality care over the long term. These realities highlight the need for European states to fulfil their obligations under Article 18 of the CRC to support parents and legal guardians in their caregiving responsibilities.

Lifecycle and Future Planning

The transition to adulthood presents a particularly critical gap in support. Survey respondents frequently reported that as their autistic family members aged, the availability and quality of support services diminished sharply. Services that were somewhat accessible during childhood, such as therapies, educational support, and structured day programs, often disappeared or became increasingly difficult to obtain once the individual reached the age of eighteen. Many respondents expressed the frustration that while such supports are, on paper or in legislation provided for, the reality is that they do not exist. Instead, they face endless waitlists and services that are basically redundant due to lack of funding. This represents a discontinuity in care that undermines the right to an inclusive life trajectory, as enshrined in Articles 19 and 28 of the CRPD, ultimately leaving the burden of care back on those informal carers, mothers who are themselves aging.

Families described a sense of being abandoned by their governments at a time when the need for guidance and planning was particularly acute. Few respondents reported access to services supporting independent living, employment, or higher education for autistic adults. Some mentioned the persistence of outdated models such as sheltered workshops or residential institutions, which do not align with the principles of autonomy and inclusion promoted by the CRPD. These results reflect the data on employment that Autism-Europe has reported on previously which shows that autistic people in face one of the highest unemployment rates in Europe, approximately 85% or above.[10]

Consultation mechanisms for assessing family satisfaction with existing services were also lacking. Most families indicated that they were not given opportunities to provide feedback or participate in advisory groups or family councils. Where such processes did exist, they were often inaccessible or inadequately publicised.

The issue of inclusive policy-making was similarly fraught. While a minority of respondents reported being involved in discussions about care policies, most felt excluded. The barriers to participation included, not only the lack of formal consultation structures, but also the complexity and inaccessibility of the policy-making process itself. Data collection on the needs of autistic people and their families was widely viewed as insufficient. Many respondents were unaware of any national surveys tracking informal caregiving duties, and where data collection efforts

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[10] Autism-Europe's presentation to the European Parliament's Committee on Employment and Social Affairs on 5 November 2019: https://www.autismeurope.org/wp-content/uploads/2019/11/presentation_employment_autism_final2.pptx.pdf

did exist, they often failed to disaggregate findings by disability status. This data gap hampers the ability of policymakers to design evidence-based support systems. The absence of disaggregated data violates Article 31 of the CRPD, which obliges states to collect appropriate information to formulate and implement effective policies.

Conclusion

The data collected through Autism-Europe's survey, together with broader contextual evidence, clearly illustrate the deep structural inequalities that families, particularly mothers, face while supporting autistic children and adults across Europe. These challenges are not merely anecdotal or isolated; they reflect systemic gaps in care, social protection, and inclusion that violate the rights and dignity of autistic people and their families. The disproportionate impact on women, the strain on mental and physical health, the disruption of careers and education, and the lack of accessible, coordinated support services reflect not only gaps in national welfare systems but also a breach of international human rights obligations, including those enshrined in the CRPD, CRC, and CEDAW.

Addressing these issues requires that states take urgent, concrete action to develop and implement comprehensive support services and rights-based policies that are tailored to the needs of informal carers. This includes legislative reform to enhance the right to care leave and extend social protection schemes in ways that provide direct financial assistance, access to respite care, and flexible employment options that enable carers to remain economically and socially active.

Moreover, it is essential to create inclusive and accessible mechanisms that genuinely involve autistic people and their families in the design, monitoring, and evaluation of care policies and services. Their lived experience is a critical resource that must inform public decision-making. States should invest in the development of long-term care services that are person-centred, rights-based, and responsive across the lifespan—beginning with equitable access to early intervention and continuing through to community-based services for autistic adults that promote autonomy, dignity, and inclusion. We re-emphasise here that services should be available for all autistic people, whatever the level of support they require. Tailored solutions should be offered to individuals, those with high support need and those who are more autonomous. The undermining of a persons required level of support by States only shifts the duty of care onto families.

Reliable, disaggregated data collection is another indispensable component of effective policymaking. States must improve national efforts to track informal care duties and gather data that is broken down by disability status, gender, and age. Without such data, policies will continue to fall short of addressing the real needs of carers and the individuals they support. Finally, care policy must be rooted in a clear understanding of its gendered dimensions. Given that the vast majority of informal caregivers are women, it is imperative to promote gender-sensitive approaches that acknowledge and actively mitigate the structural disadvantages that female carers face. Without meaningful recognition of this imbalance, efforts to reform care systems will fail to achieve equity or sustainability.

In sum, the realisation of the rights enshrined in international human rights treaties, including the right to an adequate standard of living, to participation in community life, to family life, and to gender equality, depends on bold, coordinated efforts to transform the systems that currently fail so many families. Autism-Europe urges the Special Rapporteur to place these recommendations at the centre of their forthcoming report. Autism-Europe remains committed to working alongside the United Nations and other stakeholders to advance the rights and well-being of autistic people and their families. We welcome further opportunities to contribute to this vital dialogue and stand ready to support efforts toward more equitable, inclusive, and supportive care systems across Europe.