

Normative Gaps in the Protection of Mothers Caring for Children with Autism in the Special Region of Yogyakarta

Raihan Qodrian^{1*}, Nailul Husna², Nurmalia Tara³, Putri Noviana Romadhoni⁴

^{1,2} Universitas Islam Negeri Sunan Kalijaga Yogyakarta

³ Universitas Islam Negeri Sumatera Utara

⁴ Universitas Gadjah Mada Yogyakarta

*Correspondence: qodrianraihan5822@gmail.com

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Abstrak

Daerah Istimewa Yogyakarta memiliki perangkat regulasi disabilitas yang relatif lengkap, tetapi perlindungan tersebut berpusat pada anak sebagai pemegang hak dan belum mengakui ibu pengasuh sebagai subjek hukum yang memiliki hak mandiri. Penelitian ini menganalisis kekosongan norma dalam perlindungan ibu yang mengasuh anak dengan autisme, yaitu tidak adanya hak korelatif yang dapat dituntut oleh pengasuh ketika hukum membebankan kewajiban pengasuhan. Penelitian hukum normatif ini menggunakan pendekatan perundang-undangan dan konseptual, dengan studi kasus ilustratif di Daerah Istimewa Yogyakarta. Bahan penelitian mencakup peraturan nasional dan daerah, data resmi, satu wawancara mendalam semi-terstruktur dengan ibu pengasuh, serta dokumentasi kesaksian orang tua yang dipublikasikan secara terbuka sebagai data pendamping. Teori etika kepedulian Eva Feder Kittay digunakan sebagai lensa evaluatif untuk menilai distribusi beban perawatan, sedangkan konsep hak-kewajiban korelatif digunakan untuk menguji struktur normatifnya. Hasil penelitian menunjukkan perbedaan antara kegagalan implementasi dan kekosongan norma: hak anak telah dirumuskan tetapi sebagian tidak terlaksana, sementara hak mandiri pengasuh terhadap dukungan jangka panjang belum dirumuskan. Pengalaman informan dan dokumentasi media mengilustrasikan beban ekonomi, kehilangan pekerjaan, biaya terapi, dan perpindahan fungsi pendampingan ke keluarga. Artikel merekomendasikan pengakuan pengasuh dalam hukum disabilitas, hak minimum atas dukungan, cuti pengasuhan netral gender, mekanisme kerja fleksibel, serta koordinasi dengan jaminan sosial dan perlindungan anak.

Kata kunci: pengasuh; anak dengan autisme; disabilitas; kekosongan norma; hak korelatif

Abstract

The Special Region of Yogyakarta has a comparatively developed disability-law framework, yet its protection remains centred on children as rights-holders and does not recognize caregiving mothers as independent legal subjects with enforceable entitlements. This article examines a normative gap in the protection of mothers caring for children with autism: the absence of correlative rights for caregivers even though the law assigns them substantial caregiving duties. It is a normative legal study using statutory and conceptual approaches, supported by an illustrative case study in the Special Region of Yogyakarta. The materials comprise national and regional regulations, official data, one semi-structured in-depth interview with a caregiving

mother, and publicly available parental testimonies used as supplementary documentation. Eva Feder Kittay's ethics of care is employed as an evaluative lens for the distribution of care burdens, while correlative rights-and-duties analysis is used to test the legal structure. The findings distinguish implementation failure from a normative gap: children's rights are formally recognized but are not always implemented, whereas caregivers' independent rights to long-term support have not been formulated. The interview and media documentation illustrate economic dependency, labour-market exit, therapy costs, and the factual absorption of service gaps by families. The article recommends explicit recognition of caregivers in disability law, minimum support entitlements, gender-neutral caregiving leave, workplace flexibility, and coordination with social-security and child-protection regimes.

Keywords: caregiver; children with autism; disability; normative gap; correlative rights

INTRODUCTION

In Indonesian law, disability is no longer treated as a matter of charity but as a question of rights, systems, and access. Article 1 point 1 of Law Number 8 of 2016 defines a person with disability as a person who experiences long-term physical, intellectual, mental, and/or sensory limitations which, in interaction with the environment, may hinder full and effective participation on an equal basis.¹ This definition locates disability-related barriers not simply in an individual body but in an environment that fails to accommodate difference. The same law places autism within mental disability, specifically developmental disability,² so that the statutory rights of persons with disabilities also extend to children on the autism spectrum.

The population potentially covered by that framework is substantial. Statistics Indonesia has recorded more than 17.8 million persons with disabilities, while the 2022 Socio-Economic Registration indicated that approximately 10.1 million households included at least one family member with a disability.³ Normatively, Indonesia has established a rights-based framework through ratification of the Convention on the Rights of Persons with Disabilities by Law Number 19 of 2011, followed by Law Number 8 of 2016, which recognizes twenty-two categories of rights and introduces accessibility and reasonable accommodation.⁴

The Special Region of Yogyakarta occupies a distinctive place in this landscape. Provincial Regulation Number 4 of 2012 preceded the national disability statute by four years and guaranteed equal rights and opportunities for persons with disabilities to obtain education across educational units, pathways, types, and levels.⁵ Governor Regulation Number 21 of 2013 subsequently regulated inclusive

¹Undang-Undang Nomor 8 Tahun 2016 tentang Penyandang Disabilitas, Pasal 1 angka 1.

²Undang-Undang Nomor 8 Tahun 2016 tentang Penyandang Disabilitas, Pasal 4 ayat (1) beserta penjelasannya.

³Universitas Muhammadiyah Jakarta, "Mewujudkan Indonesia Inklusif: Refleksi Hari Disabilitas Internasional 2025," <https://umj.ac.id>, diakses 3 Desember 2025.

⁴Undang-Undang Nomor 19 Tahun 2011 tentang Pengesahan Convention on the Rights of Persons with Disabilities.

⁵Peraturan Daerah Provinsi Daerah Istimewa Yogyakarta Nomor 4 Tahun 2012 tentang Perlindungan dan Pemenuhan Hak-Hak Penyandang Disabilitas, Pasal 5-15.

education.⁶ The framework was complemented by Yogyakarta City Regulation Number 4 of 2019 and updated at provincial level through Regional Regulation Number 3 of 2022.⁷ It was also reinforced by the establishment of the Autism Service Centre in Sentolo, Kulon Progo, which provides assessment, integrated intervention, and parental assistance.⁸ At the level of formal regulation, Yogyakarta therefore represents a comparatively strong setting in which to test whether legal completeness for the child also produces legal protection for the caregiver.

The difficulty becomes visible when formal rules are compared with implementation capacity. Nationally, of approximately 2,197,833 children with disabilities aged five to nineteen, only 269,398, or 12.26 per cent, were enrolled in special schools or inclusive schools.⁹ The problem is therefore not only the absence of rules but also the capacity to implement them. Of 40,164 educational units enrolling learners with disabilities, only 14.83 per cent had special assistance teachers, and the absence of such teachers was the reason most frequently given for rejection by schools.¹⁰ A similar pattern appears in the Special Region of Yogyakarta. At secondary level, 51 schools requested 58 special assistance teachers while only 25 were available.¹¹ In Yogyakarta City, around 1,400 learners with disabilities were served by approximately 80 special assistance teachers against an estimated need of 130 to 150, with the number declining as some assistants became subject teachers.¹² A Disability Service Unit had not yet been established and accessible facilities remained uneven.¹³ Population mapping specific to children with autism was also unavailable.¹⁴

These gaps are not merely administrative. When public services required to realize children's rights are not delivered, the underlying state obligation does not legally disappear; rather, residual care tasks are factually absorbed by households. One mother who had cared for a child with autism for eleven years described

⁶Peraturan Gubernur Daerah Istimewa Yogyakarta Nomor 21 Tahun 2013 tentang Penyelenggaraan Pendidikan Inklusif; "Webinar UAJY Soroti Kebijakan dan Praktik Pendidikan Inklusi di DIY," Kompas.com, 9 Februari 2022.

⁷Peraturan Daerah Kota Yogyakarta Nomor 4 Tahun 2019 tentang Pemajuan, Perlindungan, dan Pemenuhan Hak-Hak Penyandang Disabilitas; Peraturan Daerah Provinsi Daerah Istimewa Yogyakarta Nomor 3 Tahun 2022 tentang Penghormatan, Pelindungan, dan Pemenuhan Hak Penyandang Disabilitas.

⁸Dewan Perwakilan Rakyat Daerah Daerah Istimewa Yogyakarta, "Komisi D Dorong Penguatan SDM dan Kelembagaan Layanan Anak Berkebutuhan Khusus," <https://www.dprd-diy.go.id>, diakses 24 Juli 2025.

⁹Kementerian Koordinator Bidang Pembangunan Manusia dan Kebudayaan, "Pemerintah Wajib Penuhi Hak Pendidikan Inklusif Bagi Penyandang Disabilitas," <https://www.kemendikbud.go.id>, diakses 20 Juli 2026.

¹⁰"17,85% Penyandang Disabilitas di Indonesia Tidak Pernah Sekolah, Apa yang Salah?", GoodStats Data, 12 Desember 2024.

¹¹"DIY Kekurangan Guru Pendamping Khusus, Begini Nasib Sekolah Inklusi," Harian Jogja, 7 Juni 2026.

¹²"Jogja Kekurangan Guru Pendamping Disabilitas, Ini Solusinya," Harian Jogja, 21 Juni 2026.

¹³Dinas Sosial, Tenaga Kerja dan Transmigrasi Kota Yogyakarta, Jumlah Penyandang Disabilitas menurut Kemantren dan Jenis Disabilitas di Kota Yogyakarta Tahun 2024 (Yogyakarta: Pemerintah Kota Yogyakarta, 2024).

¹⁴DPRD Daerah Istimewa Yogyakarta, "Komisi D Dorong Penguatan SDM"; Dewan Perwakilan Rakyat Daerah Daerah Istimewa Yogyakarta, "DPRD DIY Dorong Penguatan Pendidikan Inklusif, Soroti Kekurangan Guru Pendamping Khusus," <https://www.dprd-diy.go.id>, diakses 3 Juni 2026.

disability care as not only emotional and physical work but also an economic burden that can push women out of employment and make them dependent on a partner.¹⁵ A study of thirty-one parents of children with autism similarly found that the most frequently cited sources of resilience were personal acceptance, religious closeness, and spousal support rather than public support.¹⁶ These materials do not prove that a state obligation is juridically transferred to a family. They illustrate instead how failures of implementation can produce a factual redistribution of care burdens to persons whose own entitlements remain undefined.

This distinction is central to the article. An implementation failure exists where a legal right or institutional duty is already formulated but is not effectively performed. Normative incompleteness exists where a rule recognizes a right or duty but leaves its scope, procedure, or remedial consequences insufficiently specified. A normative gap, as used here, is narrower: the statutory framework assigns a legally relevant caregiving duty and repeatedly relies on the caregiver to make another person's rights effective, yet does not formulate an independent correlative entitlement or claim-remedy for the caregiver in relation to that long-term burden.¹⁷ Article 26 of Law Number 35 of 2014 expressly places parents under duties to care for, maintain, educate, and protect children; the correlative position of the caregiver vis-à-vis public support is not expressly formulated.

The gap is therefore asymmetrical. What is missing is not the word "caregiver" but an enforceable account of what a caregiver may claim from public institutions as the legal counterpart to sustained duties that the legal order expects the family to perform. In Hohfeldian terms, legal analysis should distinguish duties from the claims that correlate with them; a duty imposed or relied upon by law does not by itself generate a complete remedial structure for the person who bears its costs.¹⁸ This rights-duty framework supplements, rather than replaces, the ethics-of-care analysis used below.

Studies on women's and children's protection often begin from a violence paradigm that presupposes an identifiable perpetrator and a victim capable of reporting the conduct.¹⁹ That paradigm is less capable of recognizing losses that

¹⁵Rahiwati Sanusi, "Ibu dengan Anak Autis Butuh Support System, Apa yang Mesti Kita Lakukan?", *Konde.co*, 4 September 2025.

¹⁶Dian Yuliana Mukhtar, Amitya Kumara, Thomas Dicky Hastjarjo, dan M. G. Adiyanti, "Beban Pengasuhan yang Dialami Oleh Orangtua yang Memiliki Anak dengan Gangguan Spektrum Autis," *Talanta Conference Series: Tropical Medicine* 1, no. 1 (2018): 163–170.

¹⁷Pasal 10 ayat (1) Undang-Undang Nomor 48 Tahun 2009 tentang Kekuasaan Kehakiman melarang pengadilan menolak memeriksa perkara dengan alasan hukumnya tidak ada atau kurang jelas. Karena itu istilah yang dipakai dalam tulisan ini adalah kekosongan norma, bukan kekosongan hukum.

¹⁸Wesley Newcomb Hohfeld, *Fundamental Legal Conceptions as Applied in Judicial Reasoning and Other Legal Essays*, ed. Walter Wheeler Cook (New Haven, CT: Yale University Press, 1919), 35–64.

¹⁹Anggun Lestari Suryamizon, "Perlindungan Hukum Preventif Terhadap Kekerasan Perempuan dan Anak dalam Perspektif Hukum Hak Asasi Manusia," *Marwah: Jurnal Perempuan, Agama dan Jender* 16, no. 2 (2017): 112–126; Rangga Setyadi, Muhammad Yamin, dan Ibnu Affan, "Perlindungan Hukum Terhadap Perempuan dan Anak dalam Kasus Kekerasan Seksual," *Jurnal Ilmiah Metadata* 3, no. 2 (2021): 1–23; Fitri Hasan, Weny A. Dunga, dan Zamroni Abdussamad, "Perlindungan Perempuan dan Anak dalam Perspektif Hukum," *Jurnal Ilmu Sosial, Humaniora dan Seni* 1, no. 2 (2023): 317–323.

arise through compliance with legally expected care. Disability-law scholarship, meanwhile, has rightly centred persons with disabilities as rights-holders but often positions family members as part of the surrounding support environment rather than as independent rights-holders. Psychology has long documented caregiver strain through the concept of parenting stress,²⁰ yet this literature does not necessarily answer the legal question of whether caregivers themselves should hold enforceable entitlements.

Evaluations of regional disability regulations also tend to stop at measuring institutional compliance, without tracing the residual care work created when services are unavailable. This article addresses that gap in three ways. First, it moves caregiving from a purely psychological or welfare frame into a rights-and-duties analysis that treats caregivers as potential legal subjects in their own right. Second, it treats implementation failure not as the end of the inquiry but as evidence of where unmet service duties create burdens that existing law leaves without a corresponding caregiver entitlement. Third, it examines this question in a jurisdiction with an unusually developed disability-regulation framework, thereby reducing the possibility that the problem can be explained simply by the absence of regional rules.

The principal evaluative lens is Eva Feder Kittay's ethics of care. Kittay's concept of derivative dependency describes the dependency experienced by a caregiver not because of the caregiver's own impairment, but because the caregiver bears another person's dependency; her principle of *doulia* requires social support for those who provide dependency care.²¹ In this article, Kittay is not treated as a direct source of positive-law rights. It is used as a theory of justice and an evaluative lens for asking whether the distribution of care burdens produced by positive law is substantively fair.²² The separate correlative-rights analysis then tests whether the positive legal structure gives caregivers a recognizable legal position through which support can be claimed.

Against that background, this article addresses two related questions. First, where precisely is the normative gap in the protection of mothers caring for children with autism when Indonesian law already contains regimes for women, children, and persons with disabilities? Second, why can that gap persist even in a region with a comparatively complete regulatory framework? The analysis examines national and regional rules, uses selected comparative jurisdictions to identify transferable legal design elements, and then uses an illustrative Yogyakarta case and publicly available documentation to test whether the identified normative problem has a concrete social manifestation.

RESEARCH METHOD

This is normative legal research using statutory and conceptual approaches, supported by an illustrative case study rather than an empirical study designed to measure prevalence or causation. The legal object of analysis is the structure of

²⁰Astuti dan Tri Suminar, "The Experiences of Mother Who Has Children with Autism," *Indonesian Journal of Early Childhood Education Studies* 11, no. 2 (2022): 117–123.

²¹Eva Feder Kittay, *Love's Labor: Essays on Women, Equality, and Dependency* (New York: Routledge, 1999), 42–48.

²²Eva Feder Kittay, *Learning from My Daughter: The Value and Care of Disabled Minds* (New York: Oxford University Press, 2019), 145–150.

rights, duties, institutional obligations, and remedies applicable to caregiving. The statutory approach identifies whether caregivers are recognized as independent legal subjects and whether relevant public duties are specified. The conceptual approach distinguishes a normative gap from normative incompleteness and implementation failure and uses correlative-rights analysis together with Kittay's ethics of care. The Yogyakarta case is used only to illustrate how the normative structure may operate in a concrete setting; it does not "confirm" the prevalence or causal magnitude of the problem.

Primary legal materials include national legislation on human rights, labour, child protection, disability, health, and maternal-and-child welfare, with Law Number 35 of 2014, Law Number 8 of 2016, and Law Number 4 of 2024 serving as central instruments. At regional level, the study examines Special Region of Yogyakarta Provincial Regulation Number 4 of 2012 and Number 3 of 2022, Governor Regulation Number 21 of 2013, and Yogyakarta City Regulation Number 4 of 2019. Law Number 4 of 2024 is treated according to its stated scope, namely maternal and child welfare in the first one thousand days of life; it is therefore relevant to early caregiving but does not itself constitute a long-term caregiver-rights regime for developmental disability. Supporting materials come from official national and regional publications, international institutions, peer-reviewed literature, and the sources identified in the footnotes.

The illustrative primary account was obtained through a semi-structured in-depth interview with one mother caring for a child on the autism spectrum in the Special Region of Yogyakarta. The informant was selected because she had long-term caregiving experience across diagnosis, education, therapy, employment, and family change. Participation was based on consent and her identity is anonymized as Informant M. The retained research materials do not record the interview duration or whether the interview was audio-recorded; accordingly, this article does not claim verbatim-transcript analysis and treats the account only as an illustrative source. Supplementary documentation consists of parental testimonies published openly on news portals, service-organization websites, and public social-media channels between 2013 and 2026. Materials were located through common caregiver-community terms and hashtags and were included when they contained direct parental accounts, identified a concrete burden such as employment loss, treatment cost, or unavailable service, and remained traceable to a public source. Locked accounts and closed-group conversations were excluded. The materials were coded thematically by separating concrete experiences from general opinion, grouping them by substantive similarity, and relating each group to the relevant legal framework. The interview and media documentation provide illustrative support and pattern checking; they are not statistically representative evidence.

RESULTS AND DISCUSSION

Ethics of Care, Correlative Rights, and Derivative Dependency as an Analytical Framework

The most basic question is often left unstated: on what normative basis may a caregiver claim support from the state? Eva Feder Kittay answers part of this question through a critique of liberal theories of justice that imagine society as cooperation among free, equal, independent, and productive adults, thereby

rendering dependent persons and dependency workers less visible in the distribution of justice.²³

From that critique emerges the concept most directly relevant here: derivative dependency. A child with autism may experience primary dependency arising from support needs associated with the child's condition, while the mother who provides sustained care can develop a secondary or derivative dependency, including economic dependency, because she bears another person's need for care.²⁴ This distinction changes the legal framing of caregiver poverty. If dependency is treated as an individual weakness, the response is discretionary assistance; if it is understood as a foreseeable consequence of socially necessary care work, the inquiry shifts toward duties of institutional support.

Kittay formulates the reciprocal dimension through the principle of *doulia*, drawn from the idea of supporting those who provide dependency care.²⁵ In this evaluative framework, the state is not merely a benevolent third party. Public institutions already bear positive duties to realize disability, education, health, and child-protection rights; when implementation is inadequate, families frequently absorb the residual work required to keep those rights meaningful.²⁶ This article therefore speaks of factual burden-shifting, not a legal transfer that extinguishes the state's duty. The framework also answers the objection that caring for one's own child is a moral responsibility that should not be monetized: acknowledging the moral dimension of care does not justify assigning all of its foreseeable economic consequences to the person who performs it.

The legal definition of disability determines who falls within the scope of protection, which rights are triggered, and whose obligations arise. A charity model treats persons with disabilities as objects of compassion. A medical model locates the problem in the individual and places the burden of adjustment on the person and family. The social model understands disability as the interaction between an individual condition and environmental barriers.²⁷ The latter approach underlies the Convention on the Rights of Persons with Disabilities and is reflected in Indonesian law, including the shift from the terminology of "persons with defects" in Law Number 4 of 1997 to "persons with disabilities" in Law Number 8 of 2016 and in the environmental-interaction element of Article 1 point 1.

Article 4 paragraph (1) identifies four categories of disability that may occur singly or in multiple forms: physical, intellectual, mental, and sensory disability.²⁸ Autism is placed within mental disability, specifically developmental disability affecting social interaction. The legal consequence is significant: the rights recognized in Article 5 attach to children on the autism spectrum, and denial of those rights is a legal issue rather than merely an internal institutional policy choice.

Autism spectrum disorder is a neurodevelopmental condition affecting communication, social interaction, and sensory processing, commonly accompanied

²³Kittay, *Love's Labor*, 14–21.

²⁴Kittay, *Love's Labor*, 42–48.

²⁵Kittay, *Learning from My Daughter*, 145–150.

²⁶Kittay, *Love's Labor*, 107–113.

²⁷Michael Oliver, *The Politics of Disablement* (London: Macmillan Education, 1990), 11–18; Michael Oliver, "The Social Model of Disability: Thirty Years On," *Disability & Society* 28, no. 7 (2013): 1024–1026.

²⁸Undang-Undang Nomor 8 Tahun 2016 tentang Penyandang Disabilitas, Pasal 4 ayat (1).

by restricted or repetitive patterns of behaviour and interests. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders consolidated several previously separate diagnoses into a single spectrum categorized by the level of support required.²⁹ Individual variation makes reasonable accommodation more appropriate than policies that generalize across all disabilities. Two policy implications are particularly relevant: autism is a lifelong developmental condition rather than a temporary illness, and support needs are not eliminated simply by intelligence or academic ability.

Indonesia does not have an official national survey specifically measuring the prevalence of autism among children. The Ministry of Health has acknowledged the absence of a dedicated national prevalence study, so estimates often draw on prevalence figures from other jurisdictions or international studies.³⁰ The World Health Organization has cited global estimates of around one in one hundred children.³¹ The widely circulated figure of 2.4 million children in Indonesian media is an extrapolation rather than a national enumeration.³² This does not mean that Indonesia has “no disability data at all”: administrative and household disability datasets exist, but they do not provide a nationally representative autism-specific prevalence estimate. The limitation is legally relevant because Law Number 8 of 2016 imposes governmental data responsibilities, and policy design for a subgroup is difficult when the subgroup is not separately measurable.³³

The first framework derives from Indonesia’s ratification of the Convention on the Elimination of All Forms of Discrimination against Women through Law Number 7 of 1984 and is reinforced by Article 49 of Law Number 39 of 1999, Law Number 23 of 2004, and Law Number 12 of 2022. This body of law largely sees women as victims of violence and as workers. In the latter capacity, protection includes menstrual leave, maternity leave, and breastfeeding time under Articles 81 to 83 of Law Number 13 of 2003. Law Number 4 of 2024 further provides at least three months of maternity leave, extendable for another three months under specified conditions.³⁴ That statute is an important development, but its legal title and design expressly concern maternal and child welfare during the first one thousand days of life. It therefore addresses a defined early-life phase and does not establish long-term entitlements for caregivers whose children have lifelong developmental support needs.

The second framework rests on Article 28B paragraph (2) of the 1945 Constitution and is elaborated by Law Number 35 of 2014, which treats children as autonomous rights-holders. Article 26 is especially relevant because it places

²⁹American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, ed. ke-5 (Washington, DC: American Psychiatric Publishing, 2013), 50–59.

³⁰Kementerian Kesehatan Republik Indonesia, “Autisme Ada di Sekeliling Kita, Mari Wujudkan Kepedulian Kita!”, <https://kemkes.go.id>, diakses 20 Juli 2026.

³¹Jinan Zeidan dkk., “Global Prevalence of Autism: A Systematic Review Update,” *Autism Research* 15, no. 5 (2022): 778–790.

³²“Prevalensi Gangguan Spektrum Autisme di Indonesia Meningkat karena Paparan BPA?”, *Liputan6*, 13 April 2023.

³³Undang-Undang Nomor 8 Tahun 2016 tentang Penyandang Disabilitas, Pasal 27.

³⁴Undang-Undang Nomor 4 Tahun 2024 tentang Kesejahteraan Ibu dan Anak pada Fase Seribu Hari Pertama Kehidupan, Pasal 4 ayat (3) dan Pasal 5.

parents under duties to care for, maintain, educate, and protect children.³⁵ The provision is directionally asymmetrical: it clearly formulates parental duties but does not set out a corresponding caregiver entitlement to public support tailored to situations in which a child's needs substantially exceed ordinary household capacity.

The third framework is conceptually the most advanced. Law Number 8 of 2016 guarantees twenty-two categories of rights and introduces accessibility and reasonable accommodation, reinforced by Government Regulation Number 13 of 2020. Yet Article 24, although framed around family-related rights, grants rights to persons with disabilities to form a family, have children, and enjoy family life; it does not formulate an independent caregiver right held by the family member who provides care.³⁶ Family members consequently remain important implementation actors, but their own economic and psychosocial position is not constructed as a separate rights-bearing category.

Table 1. Position of Caregiving Mothers within Three Protective Legal Frameworks

No.	Protective framework	Legal position of caregiving mother	What remains legally invisible
1	Women's protection (Law 7/1984, Law 39/1999, Law 23/2004, Law 13/2003, Law 12/2022, Law 4/2024)	Victim of violence or worker during pregnancy, maternity, and breastfeeding	Long-term care beyond the first one thousand days and income loss caused by intensive caregiving
2	Child protection (Law 23/2002 as amended by Law 35/2014 and Law 17/2016)	Bearer of parental caregiving duties under Article 26	Parents' actual care capacity and an independent entitlement to public support
3	Disability protection (Law 19/2011, Law 8/2016, Government Regulation 13/2020)	Part of the support environment surrounding the person with disability	Caregiver as an independent rights-holder and the economic consequences of care

Source: Authors' synthesis of the relevant legislation.

The final column of Table 1 shows a consistent pattern. Each framework sees the caregiving mother primarily through a role performed for someone else: as a woman protected against a perpetrator of violence, as a parent responsible for realizing a child's rights, or as part of the support environment surrounding a person with disability. None squarely addresses the caregiver as a person who may sustain legally relevant losses and therefore require an independent route to support. The repetition of this pattern across different statutes is what makes the problem structural rather than a drafting omission in a single provision.

³⁵Undang-Undang Nomor 35 Tahun 2014 tentang Perubahan atas Undang-Undang Nomor 23 Tahun 2002 tentang Perlindungan Anak, Pasal 26.

³⁶Undang-Undang Nomor 8 Tahun 2016 tentang Penyandang Disabilitas, Pasal 24.

Caregiving Burdens: Education, Employment, and Cost

Education data indicate that school availability is one of the most consequential conditions affecting whether a mother can remain in paid employment; the evidence does not justify treating it as a single universally determinative variable. UNICEF Indonesia reported that almost 30 per cent of children with disabilities had never entered a classroom, and only 54 per cent completed primary education compared with 95 per cent of children without disabilities; at upper-secondary level the gap widened to 26 per cent versus 62 per cent.³⁷ More recent data show a related pattern: 18.99 per cent of persons with disabilities had never attended school, 25.92 per cent had not completed primary school, and 28.86 per cent had completed only primary school, so that cumulatively 73.77 per cent stopped before completing junior-secondary education.³⁸

This is where the social model adopted by Law Number 8 of 2016 simultaneously clarifies the problem and exposes implementation weakness. A shortage of special assistance teachers is an environmental barrier; when that barrier is not removed, the assistance function is often transferred in practice from the classroom to the household. The limited number of special schools 2,379, with 41.19 per cent concentrated on Java also creates geographic barriers for families outside Java.³⁹

School exclusion can therefore translate an education-policy failure into reduced labour-market participation for women. In the broader labour context, the August 2024 National Labour Force Survey recorded women's labour-force participation at 55.42 per cent, substantially below men's.⁴⁰ Globally, women perform 76.2 per cent of unpaid care hours, or 3.2 times as much as men, while men in Asia and the Pacific contribute among the lowest average daily care hours worldwide.⁴¹

In Indonesia, a social experiment involving five women recorded that four spent more than forty hours per week on caregiving, exceeding a standard full-time working week; one participant recorded 103.58 hours per week, valued at approximately IDR 23 million per month if remunerated at applicable wage standards.⁴² Those figures concerned women caring for children without disabilities, while research on parents of children with autism has reported care commitments reaching around sixty hours per week.⁴³ Globally, 708 million women are outside the labour force because of unpaid care responsibilities compared with

³⁷UNICEF Indonesia, *Anak dengan Disabilitas dan Pendidikan* (Jakarta: UNICEF Indonesia, 2020), 2–4.

³⁸"Penyandang Disabilitas Masih Didominasi Lulusan SD ke Bawah," GoodStats Data, 2 Desember 2025.

³⁹"17,85% Penyandang Disabilitas di Indonesia Tidak Pernah Sekolah."

⁴⁰Badan Pusat Statistik, *Keadaan Angkatan Kerja di Indonesia Agustus 2024* (Jakarta: Badan Pusat Statistik, 2024), 45.

⁴¹International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work* (Geneva: ILO, 2018), 43–52.

⁴²International Labour Organization, "ILO-Magdalene Social Experiment: Women Spend 100 Hours of Unpaid Care Work a Week," <https://www.ilo.org>, diakses 2 Agustus 2026.

⁴³Krister Järbrink, Eric Fombonne, dan Martin Knapp, "Measuring the Parental, Service and Cost Impacts of Children with Autistic Spectrum Disorder: A Pilot Study," *Journal of Autism and Developmental Disorders* 33, no. 4 (2003): 395–402.

about 40 million men.⁴⁴ These data do not establish causation in the Yogyakarta case, but they provide a broader gendered context for understanding why intensive care can generate disproportionate labour-market effects for women.

The comparison is functional rather than jurisdictional copying. The United States, Australia, Sweden, Norway, the United Kingdom, and Japan are used because the cited studies or statutes provide observable legal or policy mechanisms concerning employment, caregiver leave, income replacement, or publicly supported care. The comparison asks which design elements respond to the specific legal problem identified in Indonesia: recognition of caregiving as a legally relevant burden, time protection from employment, income support, and service provision. Elements dependent on very different fiscal, social-insurance, or labour-market structures cannot simply be transplanted; they serve instead as evidence that caregiver burden can be reduced through institutional design.

A particularly precise estimate of the economic effect of caring for a child with autism comes from an analysis of the United States Medical Expenditure Panel Survey for 2002–2008. Mothers of children with autism spectrum disorder earned 35 per cent less than mothers of children with other health limitations and 56 per cent less than mothers of children without health limitations, and worked an average of seven fewer hours per week; no statistically meaningful labour-market difference was identified for fathers.⁴⁵ This gender concentration suggests that economic loss is not an inevitable and gender-neutral consequence of disability care.

Comparable patterns appear elsewhere. In Australia, mothers of children with autism were substantially more likely to be outside the labour force, with informal care frequently cited as the reason.⁴⁶ In Sweden, parents of children with autism were more likely to take sickness absence and have lower income, with stronger associations for mothers.⁴⁷ Research in the United States similarly reports smaller reductions in working hours among fathers.⁴⁸ A direct comparison found that, after controlling for sociodemographic factors, United States mothers caring for children with moderate-to-severe autism had a probability of employment about 25 percentage points lower, compared with about 13 percentage points in Norway; the difference was linked to the availability of affordable care services.⁴⁹ Other

⁴⁴International Labour Organization, "Unpaid Care Work Prevents 708 Million Women from Participating in the Labour Market," <https://www.ilo.org>, diakses 29 Oktober 2024.

⁴⁵Zuleyha Cidav, Steven C. Marcus, dan David S. Mandell, "Implications of Childhood Autism for Parental Employment and Earnings," *Pediatrics* 129, no. 4 (2012): 617–623.

⁴⁶Emily J. Callander dan Daniel B. Lindsay, "The Impact of Childhood Autism Spectrum Disorder on Parent's Labour Force Participation," *Autism* 22, no. 5 (2018): 542–548.

⁴⁷Michelle McEvilly, Susanne Wicks, dan Christina Dalman, "Sick Leave and Work Participation among Parents of Children with Autism Spectrum Disorder in the Stockholm Youth Cohort," *Journal of Autism and Developmental Disorders* 45, no. 7 (2015): 2157–2167.

⁴⁸Brian P. McCall dan Elizabeth M. Starr, "Effects of Autism Spectrum Disorder on Parental Employment in the United States," *Community, Work & Family* 21, no. 4 (2018): 367–392.

⁴⁹Idunn Brekke, Andreea Alecu, Celestia Ohrazda, dan Jiwon Lee, "Implications of Childhood Autism Spectrum Disorder for Maternal Employment: United States vs. Norway," *Maternal and Child Health Journal* 28, no. 10 (2024): 1707–1715.

comparative work likewise indicates that parental income inequality associated with high care needs is shaped by family-policy design.⁵⁰

Recognition of caregivers also appears in concrete statutory mechanisms. The United Kingdom uses two routes. The Carer's Leave Act 2023, effective from 6 April 2024, gives employees a day-one right to take up to one week of unpaid leave in each twelve-month period to provide or arrange care for a dependent with long-term care needs.⁵¹ Carer's Allowance provides a weekly benefit for persons who provide at least thirty-five hours of care per week.⁵² Japan provides family-care leave of up to ninety-three days per family member, capable of being divided into periods, with an allowance equivalent to a proportion of wages, together with short-term care leave.⁵³ These mechanisms cannot be copied wholesale into Indonesia, but they show legally recognizable design options: protected time, income replacement, and explicit recognition of family care as a social risk.

Inclusive Regulation in Yogyakarta

The Special Region of Yogyakarta is among the Indonesian jurisdictions with the most developed formal disability framework. Regional Regulation Number 4 of 2012 guarantees education rights for persons with disabilities across educational units and pathways.⁵⁴ Governor Regulation Number 21 of 2013 regulates inclusive education.⁵⁵ The framework is complemented by Yogyakarta City Regulation Number 4 of 2019 and Provincial Regulation Number 3 of 2022.⁵⁶ The Autism Service Centre in Sentolo adds institutional recognition that children on the autism spectrum may require specialized services that cannot be left entirely to families.

The problem emerges when this legal architecture is compared with implementation capacity. A July 2025 working visit by Commission D of the Regional House of Representatives identified limited human resources and long service queues, alongside the more basic problem that the population of children with autism had not been mapped, so the number of children requiring and receiving services was unknown.⁵⁷ This has direct legal significance. A region may possess regulations, an inclusive-education framework, and a publicly supported autism service centre, yet still lack the data necessary to plan budgets and personnel. If children with autism are not separately mapped, the caregivers behind those children are even less likely to appear in planning and budgeting instruments.

A similar problem appears in education. Oversight of the implementation of Regional Regulation Number 3 of 2022 recorded the absence of a Disability Service

⁵⁰Jonas Vinck dan Idunn Brekke, "Gender and Education Inequalities in Parental Employment and Earnings When Having a Child with Increased Care Needs: Belgium versus Norway," *Journal of European Social Policy* 30, no. 4 (2020): 495–508.

⁵¹Acas, "Carer's Leave," <https://www.acas.org.uk/carers-leave>, diakses 2 Agustus 2026.

⁵²Carers UK, "The Carer's Leave Act 2023," <https://www.carersuk.org>, diakses 2 Agustus 2026.

⁵³Japanese Law Translation, "Act on Childcare Leave, Caregiver Leave, and Other Measures for the Welfare of Workers Caring for Children or Other Family Members," <https://www.japaneselawtranslation.go.jp>, diakses 2 Agustus 2026.

⁵⁴Peraturan Daerah Provinsi Daerah Istimewa Yogyakarta Nomor 4 Tahun 2012, Pasal 5–15.

⁵⁵Peraturan Gubernur Daerah Istimewa Yogyakarta Nomor 21 Tahun 2013.

⁵⁶Peraturan Daerah Kota Yogyakarta Nomor 4 Tahun 2019; Peraturan Daerah Provinsi Daerah Istimewa Yogyakarta Nomor 3 Tahun 2022.

⁵⁷DPRD Daerah Istimewa Yogyakarta, "Komisi D Dorong Penguatan SDM."

Unit, shortages of special assistance teachers in many schools, and uneven accessible facilities.⁵⁸ Earlier research likewise observed that inclusive schooling for children with autism is more difficult to implement than inclusion based only on physical accessibility because it requires specialized teaching capacity.⁵⁹ In demographic records, the Yogyakarta City social-service agency recorded 3,089 persons with disabilities in 2024, consisting of 2,127 persons with a single disability, 678 with double disabilities, and 284 with multiple disabilities, increasing from 2,340 in 2022.⁶⁰ Those data are organized by disability type and area, not by whether a household contains a long-term caregiver; the data architecture itself therefore does not capture the subject analysed in this article.

To illustrate whether the identified normative problem has a concrete social form, the study interviewed a mother caring for a child on the autism spectrum in Yogyakarta, referred to as Informant M. Her child, born in 2014, has high support needs and is non-speaking, and currently attends a special school with teacher assistance. The most salient feature of her account is the experience of derivative dependency. She reported leaving a career for thirteen years and, when her marriage ended, leaving the household without property other than clothing. She stated that without her writing skills she would have had no independent economic foothold.

“Being a woman in Indonesia is already vulnerable; having a child with special needs makes that vulnerability layered.”⁶¹

The account illustrates a dimension not readily visible in statutory analysis: during marriage, the economic loss associated with caregiving can be obscured by a partner’s income. Divorce does not necessarily create the loss; it may reveal a long period in which labour-market exit and reduced independent assets have accumulated without a specific legal recovery mechanism in family or employment law.

A second issue concerns diagnostic inconsistency. According to the informant, an early assessment at a referral hospital in Yogyakarta concluded that assessment was premature, another assessment in a different city reported no abnormality, and later assessments produced differing conclusions between a psychologist and a hospital. A definitive diagnosis was reached only after five different assessments over several years.⁶² This account is illustrative rather than representative. Its legal relevance is that formal recognition of disability can function as an entry point to accommodation, service eligibility, and administrative data, so prolonged uncertainty may delay access while care needs continue to be borne by the family.

Even after access was obtained, the informant described a significant gap between publicly covered therapy and the intensity of intervention she had been advised to seek. She reported public health-insurance therapy of roughly one session per week for around thirty minutes, sometimes shorter after long queues,

⁵⁸DPRD Daerah Istimewa Yogyakarta, "DPRD DIY Dorong Penguatan Pendidikan Inklusif."

⁵⁹"Penanganan Autisme di DIY Terhalang Tenaga," *Harian Jogja*, 2 April 2018.

⁶⁰Dinas Sosial, Tenaga Kerja dan Transmigrasi Kota Yogyakarta, *Jumlah Penyandang Disabilitas menurut Kemantren dan Jenis Disabilitas di Kota Yogyakarta Tahun 2024* (Yogyakarta: Pemerintah Kota Yogyakarta, 2024).

⁶¹Wawancara dengan Informan M, ibu pengasuh anak dengan gangguan spektrum autisme, Universitas Gadjah Mada, Yogyakarta, 5 September 2026.

⁶²Wawancara dengan Informan M.

while an intervention benchmark discussed with her reached up to forty hours per week. Private therapy cost hundreds of thousands of rupiah per hour, in addition to special-diet costs and special-school fees.⁶³ These figures are individual testimony and should not be generalized to all children, facilities, or benefit packages. They nevertheless illustrate how a formally available service may leave substantial residual time and cost with the household.

A third finding is the absence, in the informant's experience, of support specifically directed to the caregiver. She reported no dedicated psychological support for parents and perceived that institutional and non-governmental services concentrated on the child's recovery without treating caregiving as work that may also create support needs for the caregiver.⁶⁴ Her suggested interventions were modest: periodic counselling or, at minimum, caregiver training where the state could not finance sufficient therapy. The legal relevance lies in the absence of a clearly defined caregiver category through which such support could be routinely planned and budgeted.

The informant also observed that even institutions committed to inclusion did not necessarily provide a mechanism for male employees to take caregiving leave. In her view, fathers should be able to substitute for mothers when the mother is ill.⁶⁵ This account supports a gender-neutral design for caregiving leave and also shows why awareness alone may be insufficient without an explicit employment mechanism.

The interview was supplemented by public documentation of parental experiences between 2013 and 2026. The documentation was used to assess whether the types of burden described by Informant M also appeared in other publicly reported family experiences, not to estimate prevalence.

The first theme concerns labour-market exit and economic dependence on a spouse. One mother who had cared for her child for eleven years described the economic consequences of leaving paid work.⁶⁶ The account complements Informant M from a different household context: where a marriage remains intact, lost earnings may appear as a shift in household income sources rather than immediately as poverty, which helps explain why the loss can remain legally invisible.

The second theme concerns the compounded vulnerability of single mothers. One published account observed that autism-related care can involve significant expenses and becomes particularly difficult for a single mother without spousal support because of divorce or death.⁶⁷ Through the lens of derivative dependency, single motherhood exposes a loss that may previously have been buffered by another household income. Means-tested poverty assistance may therefore intervene only after economic deprivation has materialized rather than preventing caregiver impoverishment.

⁶³Wawancara dengan Informan M.

⁶⁴Wawancara dengan Informan M.

⁶⁵Wawancara dengan Informan M.

⁶⁶Sanusi, "Ibu dengan Anak Autis Butuh Support System."

⁶⁷ Tim Konde, "Rasanya Lelah Akut: Beban Single Mom yang Miliki Anak Autis," <https://www.konde.co/2023/10/rasanya-lelah-akut-beban-single-mom-yang-miliki-anak-autis/>, diakses 6 Agustus 2026.

The third theme concerns therapy and assistive costs, which recur frequently in parental testimonies.⁶⁸ Some accounts describe autism-related therapy, medication, supplements, and consultations being financed directly by families where insurance coverage was limited or unavailable.⁶⁹ One parent was reported to have spent up to IDR 30 million per month on a rare medication not covered by private insurance or the National Health Insurance scheme.⁷⁰ Other reporting described age-related limits on rehabilitation therapy for children with special needs.⁷¹ These accounts should not be read as a uniform statement of current national benefit rules; rather, they illustrate recurring household exposure to treatment-cost uncertainty in a lifelong developmental condition.

The fourth theme arises from public social-media channels. Hashtags concerning children with special needs, parenting, and autism contain large numbers of parent-created posts exchanging information on tantrums, speech practice, and therapy choices.⁷² Such peer exchange can be valuable, but its prominence also illustrates how families may rely on informal information ecosystems when official information on rights, referrals, and service options is difficult to navigate. The analytical point is not that government information is wholly absent, but that families may still experience information and training burdens that are not captured as part of service delivery.

Public channels also contain therapeutic claims promising rapid changes, including posts claiming dramatic behavioural improvement within twenty-four hours.⁷³ Such claims sit uneasily with the individualized and gradual character of autism support. Legally, the problem is not that every informal service is unlawful, but that vulnerable families can be required to assess quality and credibility in markets where official referral, professional standards, and consumer safeguards may be difficult to identify.

A further form of burden concerns self-provided intervention. Where trained therapists are scarce or unaffordable, some parents learn techniques from videos, workshops, or webinars and implement them at home without continuous professional assistance.⁷⁴ Here the household absorbs not only time and cost but also parts of a technical support function. Official reporting may still record that a child receives intervention, while the unpaid labour and training burden borne by the caregiver remains unmeasured.

Taken together, the four themes provide illustrative support for the interview at the level of burden type, not prevalence. The accounts span different families,

⁶⁸Malang Autism Center, "Tantangan dan Dukungan bagi Ibu dengan Anak ASD," <https://malangautismcenter.com>, diakses 7 September 2026; Rumah Sakit Santo Yusup, "Sharing Untold Story Orang Tua dari Anak Berkebutuhan Khusus," <https://www.rssantoyusup.com>, diakses 7 September 2026.

⁶⁹"Autis Tidak Dianggap Penyakit, Biaya Terapi Ditanggung Sendiri," Detik Health, 2 April 2013.

⁷⁰"Derita Anak Autis di Indonesia: Alami Diskriminasi, Obat Mahal, Tenaga Terapis Minim," Berita Jatim, 12 April 2026.

⁷¹"BPJS Sortir Layanan, Keluarga Pasien Resah," Kontan, 12 Juni 2024.

⁷²Penelusuran atas tagar "#anakberkebutuhankhusus", "#parentingabk", dan "#autisme" pada kanal video pendek TikTok, <https://www.tiktok.com>, diakses 10 September 2026.

⁷³Penelusuran tagar "#parentingabk" dan "#autisme", TikTok.

⁷⁴"Derita Anak Autis di Indonesia."

places, and years and repeatedly describe employment effects, cost exposure, information work, and self-provided care. They therefore strengthen the inference that the legal invisibility of caregiver costs is not unique to Informant M, while the limitations of non-random media documentation prevent any statistical generalization.

The materials reveal a consistent inferential chain. Positive law recognizes children's disability, education, health, and protection rights. Implementation materials show capacity constraints in teachers, specialized services, data, and access. Comparative and labour evidence shows that intensive care can affect employment and income, particularly for women. The interview and media accounts then illustrate the household-level form of those residual burdens. This does not transform implementation failure into a legal transfer of state duties. It shows instead why implementation failure becomes legally significant for the separate normative-gap inquiry: the resulting care work lands on a person whose independent entitlement to long-term support is not clearly structured in the statutes examined.

Normative Gap: The Caregiver as an Unregulated Rights-Bearing Subject

A systematic reading of the three protective frameworks produces a consistent conclusion: caregivers are expressly or functionally relied upon as duty-bearers, yet the examined statutes do not formulate a general independent entitlement to long-term caregiver support. Kittay's ethics of care explains why this allocation may be distributively unjust, while correlative-rights analysis explains why the legal structure is incomplete from the caregiver's perspective.⁷⁵ The normative gap identified here has three cumulative elements: a legally recognized caregiving duty or reliance on family care; a recurring burden necessary to make another person's rights effective; and the absence of a corresponding caregiver entitlement and accessible mechanism through which public support can be claimed. Where an entitlement exists but is poorly implemented, the problem is implementation failure rather than normative absence.

The phrase "according to the child's ability, talent, and interest" in Article 26 rests on an implicit assumption that households possess sufficient capacity to meet children's needs. That assumption becomes fragile when care involves intensive behavioural intervention, specialized educational assistance, and continuous supervision. Higher-income families may purchase private therapy, hire assistance, or select schools able to accommodate the child, while lower-income families are more dependent on unpaid household labour. Because unpaid care is distributed unequally by gender, the resulting constraint often falls disproportionately on mothers. Access to the child's rights can therefore become stratified by household resources.

Law Number 4 of 2024 is an important legal development, but its defined temporal scope also shows why a parallel long-term caregiver framework remains necessary. The statute is expressly directed to maternal and child welfare in the first one thousand days of life.⁷⁶ That phase is particularly significant for pregnancy,

⁷⁵Kittay, *Love's Labor*, 107–113.

⁷⁶Undang-Undang Nomor 4 Tahun 2024 tentang Kesejahteraan Ibu dan Anak pada Fase Seribu Hari Pertama Kehidupan, Pasal 4 ayat (3) dan Pasal 5.

birth, nutrition, and early development. Autism-related support needs, however, commonly emerge, are assessed, and continue beyond that period. The point is not that Law Number 4 of 2024 fails within its own statutory purpose; rather, it does not answer the separate legal question of sustained caregiving support across childhood and potentially adulthood.

Law Number 8 of 2016 requires reasonable accommodation for workers with disabilities, but it does not extend the same concept to workers who care for family members with disabilities. This article does not argue that existing reasonable-accommodation provisions can simply be interpreted to create such a right. The analogy is *de lege ferenda*: a future caregiver-support regime could require proportionate workplace adjustments, such as schedule flexibility or protected leave, for employees with intensive family-care responsibilities, while preserving the distinct legal meaning of reasonable accommodation for persons with disabilities. Without such a mechanism, labour-market exit by a caregiving mother may be formally voluntary even when the practical range of alternatives has been severely narrowed.⁷⁷

The available comparative evidence indicates that caregiver-related economic loss is policy-sensitive rather than inevitable. One study reported a 56 per cent income difference for mothers of children with autism compared with mothers of children without health limitations.⁷⁸ Cross-national evidence comparing the United States and Norway showed smaller employment penalties where affordable care services were more available.⁷⁹ Broader social norms also matter: survey evidence indicates that many women themselves regard leaving work for care as ordinary or expected.⁸⁰ These findings support a prescriptive conclusion that law should address the institutional distribution of care burdens rather than relying solely on discretionary charity.

This study has four principal limitations. First, the empirical material includes only one in-depth informant and therefore cannot establish prevalence or causal frequency. Second, the supplementary media documentation is purposively selected from public and traceable materials rather than a representative sample and may be affected by publication and selection bias. Third, the availability and quality of disability and caregiver support vary across regions, so the Yogyakarta illustration cannot be generalized to all Indonesian jurisdictions. Fourth, Indonesia lacks a nationally representative autism-specific prevalence dataset, which constrains quantitative estimates of the population potentially affected. The study's conclusions are therefore primarily normative; the interview and media material illustrate the operation and consequences of the identified legal structure.

CONCLUSION

The principal normative finding is an asymmetry between caregiving duties and caregiver rights. Across the women's-protection, child-protection, and disability

⁷⁷Angela Crettenden, Amy Wright, dan Natalie Skinner, "Mothers Caring for Children and Young People with Developmental Disabilities," *Community, Work & Family* 17, no. 3 (2014): 244–267.

⁷⁸Cidav, Marcus, dan Mandell, "Implications of Childhood Autism," 620.

⁷⁹Brekke dkk., "Implications of Childhood Autism Spectrum Disorder," 1711–1713.

⁸⁰International Labour Organization, "Indonesian Women Are Still Obligated to Quit Their Paid Jobs Due to Caring Responsibilities," <https://www.ilo.org>, diakses 15 November 2025.

frameworks examined, mothers caring for children on the autism spectrum are primarily treated as victims of violence, workers in pregnancy and maternity, parents carrying child-care duties, or members of a person with disability's support environment. Existing law does not yet formulate a general independent status through which long-term caregivers can claim support as rights-holders. This is distinct from implementation failure, which arises where already-recognized child or disability rights are not effectively delivered.

The illustrative empirical material shows how that structure can matter in practice: the interview and public documentation describe labour-market exit, economic dependence, treatment costs, information burdens, and the household absorption of specialized care tasks. These materials do not establish national prevalence, but they make visible the type of burden that is otherwise omitted from legal categories and administrative datasets.

The prescriptive response should begin with explicit recognition of a caregiver in disability legislation as a person who provides substantial, regular, and long-term assistance to a person with disability without thereby replacing the rights of the person receiving care. Minimum caregiver entitlements should include access to information and training, psychosocial support, gender-neutral protected caregiving leave, proportionate workplace flexibility, and access to social-protection mechanisms where intensive care materially restricts employment. Public duties should be allocated according to function: health authorities for caregiver training and service navigation, labour authorities and employers for employment protection, social-security institutions for income-risk instruments, and child-protection authorities for family-support coordination. Amendment of Law Number 8 of 2016 or a dedicated caregiver-support regulation should expressly coordinate these entitlements with labour law, social security, health law, and child protection. At regional level, immediate priorities are autism population mapping, establishment and strengthening of Disability Service Units, and sufficient professional staffing at the Autism Service Centre. Health implementing regulations under Law Number 17 of 2023 should also define clinically grounded minimum developmental-therapy benefits rather than leaving effective access solely to facility capacity.⁸¹

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⁸¹Undang-Undang Nomor 17 Tahun 2023 tentang Kesehatan, Pasal 454; "UU Kesehatan Resmi Terbit, 11 UU Ini Dinyatakan Tak Berlaku," *Hukumonline*, 9 Agustus 2023.

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