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A Review of literature of Autonomy, Rights, and the Role of the Caregiver/ Family Supporter in Accordance with Ethical and Legal Framework of Disability Care

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ABSTRACT

A caregiver is a person who provides physical and psychological care to someone, who cannot take care of themselves due to poor health, injury or having medical conditions like Alzheimer's disease, Autism, Intellectual disability, cancer, metal health conditions, stroke, traumatic brain injuries, etc, causing physical and behavioral dependence. Caregiver burnout is a state of physical, mental, and emotional exhaustion, which happens when you take care of someone else and is caused by prolonged caregiving stress. Caregiver burnout can impact a person physically, psychologically, and socially. It can have severe consequences both for the caregiver and care recipient. Caregiver autonomy refers to the right of caregivers—both professional and informal family members—to make independent choices about their own lives, careers, and the boundaries of the care they provide. Balancing this autonomy with ethical duties and legal obligations to care recipients requires navigating complex challenges. Author has tried to study various conditions leading to burn out states of care giver and different solution available through various schemes under the Disability Department in India and approaches by different countries. Ethical and legal practices are critically important in caregiving services., protecting caregiver autonomy, right prevents severe burnout, preserves personal identity, and ensures sustainable, high-quality care for the recipient over time.

Keywords

Ethical and moral philosophy ,Ethical and legal practices in Autism , Intellectual disability and elderly care , Autonomy rights of care givers , Assistive technology ,Schemes by GOI for support to families of PwDs , Support schemes to care givers of Autism under IDEA , Support schemes for caregivers under National Trust Act, RPwD Act 2016,National Trust Act , Care giver burn out , Disability , Autism , Cerebral palsy , Multiple Disabilities .

INTRODUCTION

Ethics or Moral Philosophy is a systematic treatment of ideas and principles that are indispensable for the determination of the good and the bad in human life. Ethics has to do with what is Good (A concept of Indian Philosophy and culture) for the individual or society. Ethical theories are usually divided into three areas: Metaethics, Normative Ethics, and Applied Ethics. At the heart of ethics is a concern about something or someone other than ourselves, our own desires and self-interest. Ethics is concerned with other people's interests, with the interests of society, with the 'ultimate good'. Thus, when people think ethically they are giving some thought to something beyond themselves. It is a

set of standards that a society places on itself and which helps in guiding behavior, choices and actions of its members.

The main difference between moral and legal actions is where they come from and how they are put into action: Moral actions are based on what is right or wrong to humans, and Legal actions are codified rules and regulations implemented by the government.

A caregiver is a person who provides physical and psychological care to someone who cannot take care of themselves due to poor health, injury, or having medical conditions like Alzheimer's disease, Autism, Intellectual disability, cancer, mental health conditions, stroke, traumatic brain injuries, etc, causing physical and behavioural dependence. Their role is also to provide medical care (nursing, taking care of medicines, keeping track of health, informing health services about their requirements), physical care (helping with daily routine, bathing, etc.), psychological care (emotional support), and to prepare the food. Social care (making appointments for them and accompanying them on their trips, and taking them back). Therapies such as special education, occupational therapy, physical therapy, speech and language therapy, etc. Their main responsibility is to ensure that the person they are taking care of is safe and healthy. Caregiving is usually provided by family members. But sometimes this isn't possible for a number of reasons. Therefore, a formal caregiver might need to assume the role. A caregiver, formal or informal, may encounter difficulties in caregiving. Caregiver burnout occurs when you have been caring for someone else for a long period of time, resulting in physical, mental, and emotional exhaustion. Burnout can have physical, psychological, and social effects on a caregiver. It can have severe consequences both for the caregiver and care recipient. Caregiver autonomy is the freedom of a caregiver, either a professional service or a family member, to choose their own lives, careers, and boundaries of care. Ensuring such autonomy is balanced with ethical responsibilities and legal obligations toward care recipients poses multifaceted challenges. Caregiving Burden, Stress and Burnout

Physical challenges

- Fatigue is caused by long shifts with minimal breaks.
- Assisting patients with transfers, bathing, and moving may lead to backache or injuries.
- People do not have sufficient time to exercise, eat healthy, or take care of their health, including personal medical visits, which harms their personal health.
- Emotional and mental challenges
- High levels of stress due to the demands of patient care and/or emergency situations
- Seeing patients suffer can cause sadness or emotional burnout
- When people feel that their efforts are not being appreciated, it can lead to decreased motivation and lower morale.
- Caregivers can suffer depression if a patient they care for dies.
- Being unable to maintain a balance between empathy and professionalism

Social challenges

- Long working hours have an impact on personal relations.
- May miss out on important family events or social events, leading to feelings of loneliness

Financial challenges

- Many formal carers are working on low wages and are financially insecure.
- Workplace challenges
- Lack of proper training can make you feel unprepared for handling medical emergencies or difficult patients' behaviour
- Having limited staff can lead to higher levels of caregiver burden.

Patient-related challenges

- It can be difficult to manage challenging behaviour from patients with dementia and mental health conditions such as Autism.
- Older or disabled patients might suffer from speech problems that may need alternative communication techniques.
- Balancing work and personal life
- Have difficulty balancing work and personal life

Legal & Ethical Obligations (The Limits of Autonomy)

A caregiver's autonomy is often limited by their duty of care:

- **Duty to Report Abuse:** Mandatory reporting laws apply to caregivers (healthcare workers). They are required to report any concerns or awareness of abuse, neglect, or exploitation by a vulnerable care recipient to the relevant parties.
- **Confidentiality:** Correspondence, medical and financial records, and other information concerning the care recipient are legally and ethically required to be kept confidential by the caregiver.
- **Non-Abandonment:** No one can simply walk away from a caregiver without giving proper notice and ensuring a safe transition plan for the vulnerable person, because this can have a direct negative impact on the person.
- **Avoidance of Conflicts of Interest:** To prevent exploitation of vulnerable people, professional codes prohibit caregivers from having romantic and/or financial relationships with the care recipient.

The rights of caregivers and their protection are mainly based on the Rights of Persons with Disabilities Act in India, anchored in the National Trust Act, 1999, and the Rights of Persons with Disabilities (RPwD) Act, 2016. These laws recognize and formally specify caregivers, explain legal guardianship, and help to create support for the disabled person and the caregiver.

Support & Relief Schemes

Caregivers of disabled individuals are eligible for various government-sponsored support schemes:

- **Vikaas Day Care Scheme:** This scheme, run by The National Trust, offers daytime care. To serve people with disabilities, at least 6 hours of care (3600 minutes) is required. This gives primary caregivers time to manage and to attend to their daily tasks and work.
- **Samarth Scheme:** Provides temporary or permanent residential respite for adults with disabilities in order to offer a safe place to stay for aging or overwhelmed caregivers.
- **Caregiver Cells:** The National Trust offers parent- and caregiver-based training to help educate them in proper and caring care practices.

Protection Against Social Stigma

Section 92 of the RPwD Act: Protects the disabled person and the person who cares for them from insults, intimidation, and attempts to humiliate the disabled person in front of others by imposing strict penalties (6 months to 5 years in prison plus a fine).

Support for Ethical Care

- **Advance Directives:** Making legal wishes for care arrangements early to maintain the recipient's rights.
- Training and Education: Training can be a tool for family caregivers to handle moral distress and to make decisions.
- **Ethical Guidelines:** Employers should adhere to professional codes of ethics which centre on dignity, privacy and non-discrimination.

Ethical dilemmas are often exacerbated by emotional stress and lack of resources, making proactive planning and communication essential. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is a paradigm shift from medical and charity approaches to a human rights approach, and has an impact on ethical and legal approaches to caring. It helps to shift away from paternalistic concepts of care to those that accord autonomy, dignity, and active engagement.

Key Ethical Issues in Caregiving under UNCRPD

- **Autonomy vs. Paternalism (Article 12 & 19):** A central tension exists between protecting a person (beneficence) and respecting their right to make decisions (autonomy). The UNCRPD demands moving from "substitute decision-making" (guardianship) to "supported decision-making," where caregivers facilitate the person's own will and preferences.
- **Dignity of Risk:** Caregivers are confronted with the moral dilemmas of protecting vs. allowing people to try

things out and learn from the results, instead of over-protecting them.

- Inclusive Care & Individualization: Promoting difference, rather than a "normalizing" standard, in care as a way of ensuring it is not discriminatory.
- **Respect for Privacy (Article 22):** Respecting the privacy of the person's home/life, and protecting the confidentiality of personal health information, irrespective of housing arrangement.
- **Freedom from Exploitation & Abuse (Article 16):** Protection from abuse, violence, or exploitation, especially when present in a home or institution.

Key Legal Issues in Caregiving under UNCRPD

- **Legal Capacity and Guardianship (Article 12):** The UNCRPD challenges legal systems that remove legal capacity from people with disabilities, requiring that they be recognized as equal before the law in all aspects of life.
- **Informed Consent (Article 25):** Healthcare providers must provide care of the same quality and, most importantly, obtain "free and informed consent" from the person with disabilities, not just their caregivers.
- **Right to Independent Living (Article 19):** Legal frameworks should support people with disabilities to live independently in the community, rather than being forced into institutions.
- **Reproductive Rights and Family Life (Article 23):** Ensuring individuals with disabilities are not sterilized against their will and that parents with disabilities are not separated from their children based on their disability.
- **Accessible Information (Article 21):** Legal obligations to provide information to individuals in accessible formats of their choice.

Practical Implementation Challenges

- **Lack of Training:** Caregivers and healthcare professionals often lack training in rights-based approaches, leading to reliance on outdated medical models.
- **Resource Allocation:** The UNCRPD requires a great deal of investment in community-based services and accessibility, and this is not always available.
- **Overuse of Restriction:** Even though there are laws to protect them, restrictive practices, such as locking the doors and physical or chemical restraint, are routinely used, which raises tension with Article 14 (liberty and security).

caregiving for persons with disabilities (PwDs) in India involves complex ethical dilemmas and legal challenges, often exacerbated by a lack of infrastructure, high financial burdens, and social stigma.

Legal Issues and Rights in India: Challenges

- **Rights of Persons with Disabilities (RPWD) Act, 2016:** It is a key piece of legislation that focuses on non-discrimination and on equal participation. Yet, studies on these provisions in the law suggest that their implementation would be difficult, according to Shodhganga.
- **Guardianship (National Trust Act, 1999):** The law mandates guardians to be accountable and responsible for the person with disability and her or his property, but there is difficulty in navigating through these processes for many caregivers.
- **Lack of Legal Awareness:** A lack of knowledge of their rights to support may prevent many caregivers from obtaining these services, e.g., disability pensions or educational reservations.
- **Inadequate Protection in Institutions:** Research indicates that even in caregiving facilities, the rights of the disabled are not always fully protected, leading to neglect.
- Caregivers of people with disabilities (PwDs) in the USA have several legal protections and financial assistance avenues:
- **Paid Family Caregiving:** Depending on the state, Medicaid Waivers allow family members to be paid for caregiving. Programs vary—some states let the PWD

directly hire and pay a family member, while others provide structured agency stipends.

- **Job Protections & Leave:** The national Family and Medical Leave Act (FMLA) grants eligible employees up to 12 weeks of unpaid, job-protected leave per year to care for an immediate family member with a serious health condition. Additionally, the Americans with Disabilities Act (ADA) protects caregivers from workplace discrimination, firing, or harassment based on their association with a disabled individual.
- **Veteran Support:** The VA provides the Program of Comprehensive Assistance for Family Caregivers (PCAFC) to qualifying caregivers of severely injured veterans. Benefits include monthly stipends, health insurance, and respite care.
- **Social Security & Spousal Benefits:** Caregivers of a disabled spouse or a disabled child may be eligible for Social Security Spousal Benefits, which can equal up to 50% of the disabled individual's benefit amount.
- For a caregiver in a residential/ rehab support system, they need to have mental health support, manageable work schedules, appropriate pay, and practical training. These steps reduce stress and help staff give better care.

For Mental Health and well-being, counselling sessions can be organised for stress management and brainstorming on issues related to disability care

Peer support staff to share the burden, and regular breaks in the job create a balance in work and personal life management.

Different shift of the staff also reduces the caretaking burdens.

Advanced and crisis management techniques and the latest updates on caretaking techniques need to be provided to the caretakers.

Access to medical and safety tools and updated care plans saves time.

In a high-stress environment of caregiving, appreciation of work and a bonus system are required. Ethical and legal issues are crucial in care provision as they ensure the safety, rights and dignity of individuals living in care, and set up accountability for professionals. They provide the essential base to prevent abuse, safeguard trust, and support high-quality, person-centred provision. While maintaining autonomy for the caregiver rights help to avoid burnout, maintain personal identity, and allow for providing the recipient with quality, long-term care.

Exhaustion on an emotional level is significant. It is characterised by emotional exhaustion, lower energy levels, fatigue, and difficulties in recovering from prolonged work demands (Bennett et al., 2018; Simbula et al., 2019). Although flexible work can alleviate some of the pressure, it can also amplify others, especially when employees experience heavy workloads, frequent virtual meetings, constant communication, or little separation between work and personal life (Wang et al., 2021). Employee belonging is as important, as dispersed teams may have fewer opportunities for face-to-face interaction (Lal et al., 2023). Belonging is defined as employees' perceptions of acceptance, inclusion, recognition, interpersonal support and organisational connection. Strong belonging can facilitate engagement, commitment, collaboration, and retention. Weak belonging can foster isolation, withdrawal, and turnover intentions (Imboden, 2024).

Existing literature largely conceptualizes workplace flexibility as a job resource. Schedule control, choice of location, and autonomy in task and workload adjustment can improve work–life balance and help employees to manage their responsibilities well (Dizaho et al., 2017). Increased autonomy may also convey organizational support and trust, enhancing job satisfaction and sense of belonging (Heyns & Rothmann, 2018). But benefits of flexibility depend on implementation. Employees may find flexible arrangements stressful if they are expected to be continually available, to manage increased workload on their own or to communicate outside of normal work hours (Franken et al., 2021). Thus, flexibility might buffer emotional exhaustion in supportive conditions but exacerbate it when boundaries and expectations are not clear.

Emotional exhaustion correlates with heavy workloads, ambiguous roles, lack of recovery, low managerial support, and relentless pressure (Shinde, 2025). Employees who are emotionally

exhausted have fewer psychological resources to motivate and socially participate (Kammeyer-Mueller et al., 2016). This is significant for belonging because belonging is constructed through recognition, inclusion, supportive relationships and participation in organisational life. Exhausted employees are less likely to communicate, avoid working collaboratively, and distance themselves from colleagues and organisational efforts (Ter Hoeven et al., 2016). Emotional exhaustion can thus erode belonging even with flexible policies in place (Olaus et al., 2025).

Flexibility and belonging have a similarly complicated relationship. Flexibility in work can enhance a sense of belonging when employees perceive it as a sign that the organisation values their individual needs and trusts them to manage their work (Miller, 2023). By contrast, remote and hybrid arrangements may constrain opportunities for spontaneous interaction, visibility in the workplace and access to informal networks. As a result, employees can feel less acknowledged or engaged in organisational decisions (Adebisi & Balogun, 2026). The presence of these opposite effects suggests that the interaction of workplace flexibility and emotional exhaustion should be considered in explaining employee belonging in post-pandemic organisations.

The focus on flexible work, employee wellbeing and organisational connectedness is growing, but gaps remain. Research on workplace flexibility has often been concerned with its effects on productivity, job satisfaction, or work–life balance. There are fewer studies integrating flexibility, emotional exhaustion, and employee belonging in one empirical framework. Studies also frequently assume that flexible work is uniformly good or bad, without thinking about the emotional experiences of employees. Engagement and commitment have been widely studied, while belonging has received less attention - especially in remote, hybrid, flexible-hour, and on-site arrangements. Also, there is limited evidence across multiple organisational sectors.

The study aimed to assess workplace flexibility, emotional exhaustion, and employee belonging in post-pandemic organisations. It specifically workplace flexibility and emotional exhaustion; examine the association between workplace flexibility and employee belonging; and evaluate the relationship between emotional exhaustion and employee belonging. It also aimed to compare the reported levels of these variables across remote, hybrid, flexible-hour, and on-site work arrangements and provide practical guidance for employee-centred workplace policies and management practices.

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