NCPEDP

NCPEDP - Javed Abidi Fellowship on Disability

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Baseline Report

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Needs Assessment towards Caregiving for Disabled Persons

Contents

1 Acknowledgements

I want to express my heartfelt gratitude to the following organisations for their invaluable contribution and support in creating this baseline report on caregiving.

National Centre for Promotion of Employment for Disabled People (NCPEDP), for their unwavering commitment to promoting the rights and inclusion of persons with disabilities. Their insights and expertise have greatly enriched my understanding of the caregiving landscape.

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Without their contribution, this report would not have been possible. Thank you for your unwavering commitment to the cause of caregiving and disability rights.

2 Executive Summary

The main objective of Article 1 of the United Nations Convention is to ensure the complete and equal enjoyment of human rights and fundamental freedoms by all individuals with disabilities. It aims to protect the inherent dignity of Persons with Disabilities and promote respect for their rights.

Human Rights Treaty is crucial as it addresses the significant challenges faced by people with disabilities worldwide, who often struggle to fully experience the rights that able-bodied individuals may take for granted.

While demographic ageing is a significant factor contributing to this trend, it is not the sole reason for the worldwide increase in demand for long-term care. Several other factors also play a role, such as changing disease patterns, advancements in medical technology, increased life expectancy, urbanisation, social changes, and economic development. According to the 2011 World Report on Disability, jointly published by the World Health Organisation and the World Bank, it is projected that approximately 15% of the global population - around a billion people - will experience a disability at some point in their lives. Among them, an estimated 3.8% (195 million individuals) have significant disabilities. [1]Accessibility includes caregivers because

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[1] https://www.ncbi.nlm.nih.gov/books/NBK513078/

patients who have spinal muscular atrophy, muscular dystrophy, or cerebral palsy need full-time assistance, and they cannot move themselves without assistance. The transfer from bed to wheelchair, and wheelchair to car is a challenge.

The care of a patient with Alzheimer's disease or a related disorder can be a physical, emotional and financial drain on the family caregiver. —Diane Duouette Ascioti

Caregivers, also known as carers or support workers, play a crucial role in assisting individuals with activities of daily living when they face challenges due to old age, disability, illness, or mental disorders. Caregivers can be paid or unpaid[2].

Article 9 of the convention requires countries to adopt measures " ... to ensure to persons with disabilities, access on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas."

3 Background

The Rights of Persons with Disabilities Act, 2016 replaces the Persons with Disabilities (equal opportunities, protection of rights and full participation) Act, 1995. Under section 47(c) Human Resource Development- the appropriate government should make all endeavours to develop human resources for the purposes of this act and to initiate capacity-building programs including training in independent living and community relationships for families, members of community and other stakeholders, and care providers on caregiving and support;[3]

In a country like India where the life expectancy of older people is rising, and every person has the right to live with dignity and wellness, the aspect of caring is significant and worthy of discussion. While demographic ageing contributes to this trend, it is not the sole reason for the worldwide increase in demand for long-term care. Several other factors such as changing disease patterns, advancements in medical technology, increased life expectancy, urbanisation, social changes, and economic development also play a role. It is a matter of concern that many NGOs and charitable trusts offering care services are prohibitively expensive for families and individuals with disabilities. The high cost often makes it challenging for those needing essential caregiver support. Organisations offering such services sometimes seem more focused on profit than fulfilling their mission to serve the community.

Furthermore, the current setup often creates a barrier between disabled individuals and caregivers, with NGOs acting as intermediaries or brokers. This not only limits direct contact between the two parties but also allows for exploitation, with both, disabled individuals and caregivers, being adversely affected.

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[2] https://www.merriam-webster.com/dictionary/caregiver

[3] www.indiacode.nic.in

Both, the government and the private sector, must address this issue and take proactive steps to ensure that affordable and accessible caregiver services are available to all who need them. Every individual, regardless of their disability status, deserves to live with dignity, cleanliness, and independence.

4 Geography

Uttar Pradesh, often abbreviated as UP, is a significant state in India in terms of population and historical significance.

Bordered by the states of Uttarakhand, Himachal Pradesh, Haryana, Delhi, Rajasthan, Madhya Pradesh, Chhattisgarh, Jharkhand, and Bihar, the state has a diverse economy that includes agriculture, manufacturing, and service sectors. It is known for its agricultural produce like wheat, sugarcane, rice, and fruits.

Uttar Pradesh has been a cradle of ancient civilisations and empires. It is home to several historical and religious sites like the Taj Mahal in Agra, the Kashi Vishwanath Temple in Varanasi, and the Akshardham Temple in Lucknow.

The state has a rich cultural heritage with a mix of Hindu, Muslim, and other traditions. Festivals like Diwali, Eid, and Holi are celebrated with much enthusiasm across the state.

Uttar Pradesh plays a crucial role in Indian politics due to its large population and number of parliamentary seats. It is often considered a bellwether state, reflecting the national political mood. Many political leaders who have played a significant role in shaping India's political landscape were born here.

Despite its rich resources and potential, Uttar Pradesh faces challenges like poverty, unemployment, and a lack of infrastructure development. Overpopulation and inadequate healthcare and education facilities are other concerns.

A major tourist destination in India, it offers historical sites and areas of natural beauty such as the Dudhwa National Park and the Chambal Wildlife Sanctuary. The promotion of tourism with initiatives like the UP Tourism campaigns attracts domestic and international tourists.

In essence, Uttar Pradesh is a state of contrasts - a blend of rich history, vibrant culture, and the challenges of modernisation. Its significance in India's socio-economic and political landscape cannot be overstated.[4]

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[4] https://en.wikipedia.org/wiki/Uttar_Pradesh

5 Disability Census

In 2011, Uttar Pradesh and Maharashtra had the largest share of the disabled population among all Indian states and union territories, accounting for 15.5% and 11.05% respectively. Bihar and Andhra Pradesh followed with less than 9% each. Each of the remaining states and union territories had less than 1% of the disabled population.[5]

6 Study Plan

Objectives

The primary objectives of this study are:

1. To identify the reasons and factors contributing to the unavailability of caretakers for Persons with Disabilities (PWDs) in the Lucknow district.

2. To assess the impact of caretaker unavailability on the well-being and daily lives of PWDs in the study area.

3. To explore the coping mechanisms employed by PWDs in the absence of formal caretaker support.

4. To provide valuable insights and information to policymakers and support organisations to develop targeted interventions and support systems for PWDs in the Lucknow district.

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[5] www.statista.com

By achieving these objectives, this study aims to contribute to a better understanding of the challenges faced by PWDs in securing caretaker support, ultimately leading to improved care and support services for this vulnerable population in the Lucknow District.

Abstract

This study aims to investigate the unavailability of caretakers for PwDs in the Lucknow district of Uttar Pradesh. PwDs often require specialised care and support, and the absence of reliable caretakers can significantly impact their well-being and quality of life. The research will employ a mixed-method sequential explanatory design, combining quantitative surveys and qualitative interviews to gain comprehensive insights into the factors influencing caretaker availability. Stratified random sampling will be used to obtain a representative sample of PwDs in the Lucknow district. Data analysis will involve descriptive and inferential statistics for quantitative data and thematic analysis for qualitative data.

The study aims to contribute valuable information for policymakers and support organisations to develop targeted interventions and support systems, ultimately improving the overall quality of life for PwDs in the Lucknow district.

Introduction

The lack of available caretakers for PWDs is a pressing problem that significantly impacts the overall welfare and day-to-day experiences of individuals living with various forms of disabilities. PwDs often require continuous assistance and support to perform daily activities and access essential services. However, for several reasons, finding and retaining qualified and reliable caretakers can be challenging, leading to a lack of proper care and support for PwDs.

This study aims to explore the factors contributing to the unavailability of caretakers for PwDs in the Lucknow District of Uttar Pradesh, to understand the challenges this vulnerable population faces, and to identify potential interventions to address the issue.

Approach

This study will employ a mixed-method research design to obtain comprehensive insights into the unavailability of caretakers for PwDs. This approach will combine qualitative and quantitative data to ensure a holistic understanding of the factors influencing caretaker availability.

Research Design

For this study, we have opted for a sequential explanatory research design. This approach involves collecting quantitative data, supplemented with qualitative data for a deeper understanding of the quantitative findings. This approach enables a thorough investigation of the research subject, leading to a more profound comprehension and contextualisation of the statistical findings.

Population and Sampling Method

The population for this study will be individuals with different types of disabilities facing challenges in finding or retaining caretakers, and individuals who have worked or are currently working as caretakers for PwDs. A stratified random sampling method will be employed to obtain a representative sample. Stratification will be based on the type of disability to ensure adequate representation of various PwD categories.

Data Collection Methods

1. Quantitative Data: A structured survey will be conducted to gather quantitative data. The survey will include questions related to the participant's demographic information, disability type, previous caretaker experiences, reasons for caretaker unavailability, and the impact of this unavailability on their daily lives.

Collected by Google Form

2. Qualitative Data: Semi-structured interviews will be conducted with a subset of survey participants to delve deeper into their experiences and perspectives. These interviews will allow for a more nuanced understanding of the challenges faced by PWDs in securing caretakers and any potential coping mechanisms they may have developed.

Case study, Interviews, sessions

Research Questions

1. **For each accessibility, how many people required the assistance of a caregiver?**
2. **What are the rates of formal caregivers?**
3. **How many NGOs provide services only for PwDs?**
4. **What made a caregiver professional?**

Data Collection Procedures

1. The survey will be administered online and offline, based on the participants' preferences and accessibility.
2. Potential interviewees will be selected from survey respondents, ensuring a diverse range of disability types and geographical locations.
3. Informed consent will be obtained from all participants before data collection.

Data Analysis Strategies

1. **Quantitative Analysis:** Descriptive statistics will be used to summarise the survey data and inferential statistics. Chi-square tests will be employed to identify significant associations between variables related to caretaker unavailability.
2. **Qualitative Analysis:** Thematic analysis will be applied to the interview data to identify recurring themes and patterns related to caretaker challenges among PwDs.

Conclusion

The study on the unavailability of caretakers for PwDs sheds light on a critical issue that affects the well-being and daily lives of individuals with different types of disabilities. By adopting a mixed-method sequential explanatory research design, this study endeavours to provide a comprehensive understanding of the factors contributing to the scarcity of caretakers. By combining quantitative and qualitative data, the study aims to offer valuable insights that can inform policymakers, disability support organisations, and communities to develop targeted interventions and support systems, ultimately improving the overall quality of life of PwDs.

7 Secondary Research

The National Trust of the Ministry of Social Justice and Empowerment (MSJE), Government of India, has various schemes for including divyangjan in the mainstream.

The Vikaas (Day Care) Scheme aims to provide caregiving support to PwDs during the time a PwD is in the Vikaas centre. The Samarth (Respite Care) Scheme provides a respite home for PwDs from Below Poverty Line and Low-Income Group families, including basic medical care from professional doctors.

The Sahyogi (Caregiver Training) Scheme aims to set up Caregiver Cells (CGCs) to create a skilled workforce of caregivers who can provide adequate and nurturing care for PwDs and their families who require it.[6]

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[6] thenationaltrust.gov.in

National Trust Budget 2020-21

Sahyogi Scheme

Apart from setting up CGCs, the scheme seeks to provide parents with an opportunity to get trained in caregiving, if they so desire. It provides a choice of training through two levels of courses - primary and advanced - to create care associates suited to work both with PwD families and institutions (NGOs, work centres) catering to the needs of the divyangjan.

56 caregiver training centres set up under the scheme have trained 1762 caregivers during the past six years. Under the scheme, Rs 179.81 lakh has been released, so far. At present, the scheme is open only to the north-eastern states. Within the MSJE, the Department of Empowerment of Persons with Disabilities (DEPwD) plays a primary role in addressing the needs of PwDs, either independently or in collaboration with other ministries. An analysis of the DEPwD's budget from FY 2016–17 to FY 2023–24 indicates that while the allocation to the department steadily increased until FY 2020–21, it later experienced a decline and stagnation. Nonetheless, the overall budget allocation for the MSJE witnessed a 12% increase between FY 2021–22 and FY 2022–23.

The budgets for disability-related schemes under the DEPwD and the Ministry of Rural Development (MoRD) did not experience the same level of increase as the Ministry of Health and Family Welfare (MoHFW) from FY 2022–23 to FY 2023–24. The disability-related budgets under MoHFW witnessed a significant increase of 25% during this period. However, it is noteworthy that these increased funds are distributed among only two organisations.[7]

Sahyogi Care Associate Training Scheme	0.00	22-23	BALANCE SHEET
	2,66,800.00	21-22	
Sahyogi Care Associate Training Scheme	0.00	19-20	
	14,63,000.00	18-19	
Sahyogi Care Associate Training Scheme	0.00	20-21	
Sahyogi (Caregiver Training Scheme)	46.82	2016–17	Scheme-wise Expenditure
	118.36	2017–18	
		2018–19	
		2017–18	
		2018–19	

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[7] www.thenationaltrust.gov.in

8 Reason for failure of the Sahyogi Scheme

Challenges In the care-taking sector for Persons with Intellectual and Developmental Disabilities (PwIDDs), particularly those with severe and profound disabilities:

(a) Low Wages and Perception of Job: Care-taking roles in residential centres often involve demanding tasks like nursing and cleaning, yet they are undervalued and paid low wages. Many individuals who take up these jobs do so because they may not have other employment opportunities. This can lead to a situation where the workforce comprises individuals who may not have a genuine interest in or aptitude for caregiving, resulting in suboptimal care for PwIDDs. The lack of government support for such centres exacerbates the issue.

(b) Education Level of Caretakers: It is concerning that many caretakers in these settings have minimal education, which may impact their ability to understand and implement best practices in caregiving. Lack of education can also limit their opportunities for career advancement or specialised training in disability care.

(c) Shortage of Staff and Training Opportunities: The perpetual staff shortage in residential centres means that caretakers are often stretched thin and unable to spare time for training. This perpetuates a cycle where caregivers may not have the necessary skills or knowledge to provide optimal care for PwIDDs, further contributing to the challenges.

Due to these reasons, there were no takers for the National Trust’s Sahyogi Scheme, but this critical requirement remains unfulfilled. In essence, the shortage of caregivers in India stems from various interconnected factors. Firstly, societal perceptions often devalue caregiving roles, leading to a lack of respect and prestige associated with such professions. Additionally, the absence of stable employment conditions and competitive wages makes caregiving less attractive than other higher-paying jobs. Consequently, individuals may leave caregiving roles in pursuit of better opportunities, exacerbating the shortage of caregivers. There is a significant need to change the perception that individuals in prestigious professions like Engineering, Medicine, or Chartered Accountancy will never work as caregivers due to issues of respect. Instead, it must be recognised that anyone, regardless of their profession, can and often does serve as a primary caregiver for their disabled relatives or family members.

In summary, both, the private and government sectors often hire individuals with minimal education, sometimes not even 12th grade, for caregiving roles supporting disabled people. These positions typically offer low wages, around Rs 4500, which may not adequately reflect the critical nature of the job. Consequently, many employees may not fully understand the importance of their role or feel motivated to commit to it. As a result, turnover rates are high, with some individuals not showing up after training or leaving for higher-paying jobs elsewhere.

Lack of awareness is a significant reason for the failure of the Sahyogi Scheme. When I contacted various individuals and collected case studies and responses, most were unaware of the scheme. Similarly, even among some members of the National Trust, there was only a general awareness of the scheme’s existence, but not an understanding of the root causes of its failure. However, one officer from the National Trust provided insightful reasons contributing to the scheme's shortcomings. He informed me that one of the key issues is the lack of a fixed compensation agreement between caregivers and the families of individuals with disabilities.

Over 95% of caregivers in residential centres have never undergone any Rehabilitation Council of India-recognised training. They learn on the job, which means that effective and ineffective practices of the residential centre are perpetuated, potentially leading to substandard care. Caregiving in a residential centre involves tasks such as nursing and cleaning individuals with severe and profound intellectual developmental disabilities. Consequently, this role often attracts individuals unable to secure other types of employment, which is a harsh reality.

The officer also highlighted another significant post-implementation issue; the mismatch between caregivers and disabled families. Many trained caregivers are relatively young and seek permanent positions with decent salaries, respect, and career advancement opportunities. However, these expectations often clash with the realities of caregiving for disabled individuals, where families may have varied expectations regarding work duties and salaries. Negotiating satisfactory terms for both parties becomes challenging due to these differences in expectations.

Who provides this caregiving facility?

It appears that spouses, mothers, and daughters-in-law are the primary caregivers for PwDs, according to the NSS survey. The distribution of caregiving responsibilities is as follows:

- Spouse: 30.74%
- Mothers: 26.47%
- Daughters-in-law: 10.54%
- Sons: 9.49%
- Daughters: 4.16%
- Hired caregivers: 0.60%
- Institutional caregivers: 0.36%

Additionally, it is stated that more than 65% of caregivers are females. the International Labour Organisation has acknowledged this fact and referred to it as the *women as caregivers'* model.

In fuelling the economy and supporting other forms of work, whether it involves childcare, caring for the elderly, or domestic tasks, caregiving is often invisible and undervalued, despite being essential for the functioning of society and the economy.

Women disproportionately shoulder the burden of unpaid care work. The statistics mentioned in the statement illustrate that Indian women spend more than five hours per day on unpaid care work, while men only spend 1.37 hours on average. Because of unpaid caregiving work, women lagged in participation in paid work by 16.1%. Equity in terms of gender is becoming significant and the participation of men in caregiving should also promoted. The US recently unveiled the American Families Plan that classified *care* as essential infrastructure, marking a major shift in perception. Central and state government programs remain inadequate in catering to the needs of caregivers.

The World Economic Forum (WEF) forecast that 40% of emerging job opportunities will be in the care sector highlights the growing significance of caregiving roles in the global economy. Factors contributing to this projected increase in job opportunities are the global shift in demographics, changing social norms, and the uptick in demand for trained caregivers.[8]

The Indian Home Healthcare market has shown significant growth and potential, as indicated by the market size valued at USD 7.4 billion in 2021 and the expected Compound Annual Growth Rate of 19.27% from 2022 to 2030. The key points to consider about this market are:

1. Diverse market segments
2. Reducing hospital visits[9]
3. Cost savings for hospitals
4. Improved quality of care
5. Convenience and comfort for patients
6. Addressing healthcare access challenges

The population of India is greying. The first wave of the longitudinal ageing study in India, 2020, outlines that India continues to grow old as the population above 60 years in the country, which was 6.9 per cent in 2000, is 11.4% now.

Need for Robust Policy for Women with Disability

The term *Women and Girls with Disabilities* refers to all women with disabilities including adolescent girls and young women. *Disabilities* includes all types of impairment – physical, psychosocial, intellectual or mental, and sensory conditions with and without functional limitations. One of the key principles of the 2030 agenda is the commitment to leave no one behind. The agenda recognises the importance of gender equality and the empowerment of women and girls as fundamental to achieving sustainable development. Some of the SDGs directly related to gender equality and women's empowerment include:

1. Goal 5: achieve gender equality and empower all women and girls
2. Goal 10: reduce inequalities within and among countries, including gender inequalities

One in five women lives with a disability, making them a large population. In low- or middle-income countries, women comprise three-quarters of PwDs.

The assumption that having family around and living together ensures everything will be fine is flawed. The 2019 Nationally Representative Time Use survey revealed that women dedicate up to 75% more time to unpaid caregiving services than men. Vandana Gopikumar, co-founder of The Banyan, highlights that vulnerabilities accumulate early in a woman's life. The issue of older

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[8] www.downtoearth.org.in
[9] https://www.financialexpress.com/

sick or disabled women being abandoned in temple towns like Vrindavan has received significant media coverage. In 2012, the Supreme Court ordered the formation of a special committee to identify these women and investigate the reasons for their abandonment. However, as of 2017, The Hindu reported that this process had not yet been completed.

Furthermore, the research indicates that a significant portion of older individuals in India face limitations in their daily activities. Specifically, 23.8% report at least one Activity of Daily Limitation (ADL), signifying challenges in basic self-care tasks. Additionally, 43.8% struggle with at least one Instrumental ADL, highlighting difficulties in the tasks that are complex and involve independence in the community.

These findings emphasise the importance of addressing the needs of the ageing population in India, in terms of healthcare and social support. The statistics highlight the diverse range of challenges older individuals face, from impairments affecting various senses to limitations in daily activities. Policymakers, healthcare professionals, and communities can use this information to develop targeted interventions, improve accessibility, and enhance the overall well-being of the elderly in India.[10]

The analysis of the Rights of Persons with Disabilities (RPWD) Act, 2016, in the context of older persons with disabilities, reveals important gaps and limitations in addressing their specific needs. While the RPWD Act is a crucial piece of legislation aimed at promoting the full inclusion and participation of persons with disabilities, its focus may not adequately cover the distinct challenges faced by older individuals with disabilities.

The demographic transition in India over the past 50 years has brought about a substantial increase in the population aged above 60. This shift is significant, with the number of elderly individuals tripling during this period. According to Census 2011, 8.5% of India's population falls within the geriatric category, comprising a staggering 103 million people.

The data from the National Commission on Population reveals a significant shift in India's demographic landscape, with the share of the elderly population reaching close to 9% in 2011. Projections indicate that this proportion is expected to grow rapidly, potentially reaching 18% by 2036. This demographic transition necessitates careful planning and proactive measures to ensure a decent quality of life for the elderly in the coming years.

- Health issues like **blindness, locomotor disabilities and deafness** are most prevalent.
- **Mental illness** arising from senility (showing poor mental ability because of old age) and neurosis.
- Neurosis is a **class of functional mental disorders** involving chronic distress, but neither delusions nor hallucinations.
- Absence of geriatric-care facilities at hospitals in rural areas.

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[10] idronline.org

- According to a recent survey, **30% to 50% of elderly people had symptoms that make them depressed.** A large majority of elderly persons living alone are women, especially widows.
- Depression is strongly correlated with poverty, poor health, and loneliness.

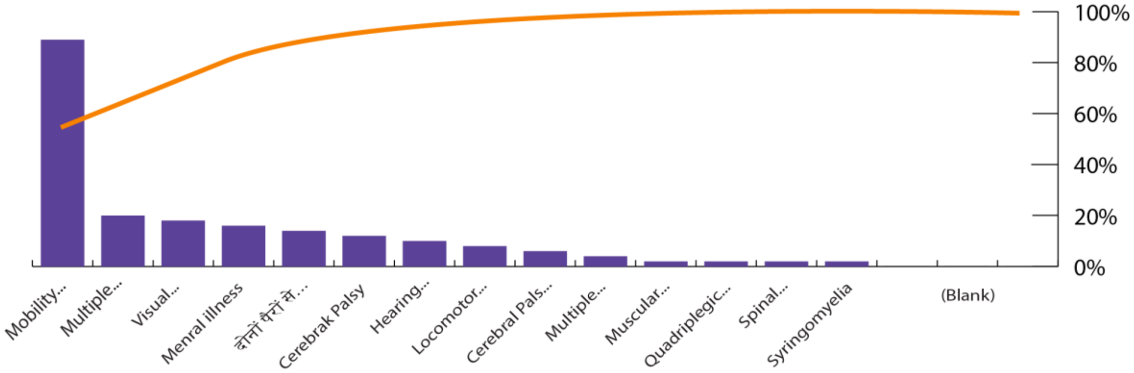
9 Primary Research

Data on the counts of individuals receiving care for various disabilities

Row Labels	Count of: Are you currently receiving care from a designated caretaker for your disability-related needs? क्या आप वर्तमान में अपनी विकलांगता-संबंधी आवश्यकताओं के लिए किसी निर्दिष्ट देखभालकर्ता से देखभाल प्राप्त कर रहे हैं?
Cerebral Palsy	3
Cerebral palsy with mental retardation	1
Hearing impairment	2
Locomotor	2
Mental illness	8
Mobility impairment	39
Multiple disabilities	11
Multiple Sclerosis	1
Muscular Dystrophy	1
Quadriplegic	1

Spinal muscular atrophy	1
Syringomyelia	1
Visual impairment	9
दोनों पैरों से विकलांग	5
(blank)	
Grand Total	85

Count of are you currently receiving care from a designated caretaker for your disbility-rekated needs?



10 Observations

High Count for Mobility Disabilities: This category has the highest count, indicating a significant need for caretaker support among individuals with mobility issues.

Multiple Disabilities: There are multiple entries, suggesting a broad category that needs clearer delineation.

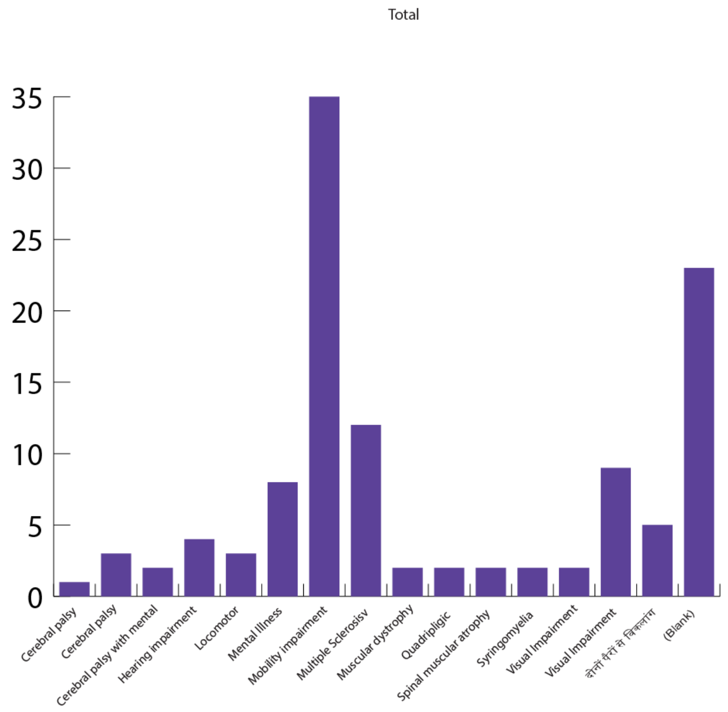
Varied Disabilities: The chart covers a range of disabilities, highlighting the diverse needs for caretaker support.

Untranslated Label: The presence of a non-English label suggests the data might come from a multilingual dataset.

Data Gaps: The "(blank)" category indicates some missing data, which could affect the overall analysis.

Analysis:

The chart effectively shows the distribution of caretaker support across different disabilities, with mobility disabilities being the most prevalent. The cumulative percentage line provides a quick view of the overall coverage, reaching 100%, which is useful for understanding the total scope.



Based on the graph provided, it is evident that locomotor disability is the most prevalent, followed by cerebral palsy and visual impairment. Persons with locomotor disabilities face difficulty using one or more of their extremities or may lack the strength to walk, grasp, or lift objects. Assistive devices like wheelchairs, crutches, or walkers may be utilised to aid in their mobility. Locomotor disability could be due to disease, injury or malformation of bones, joints, muscles, nerves, spinal cord and brain.

11 Case-Study

Empowering Caregivers: A Case for Direct Caregiver Allowance Payment

Introduction

Rajan, a resident of Uttar Pradesh, epitomises the challenges many caregivers face in India. Born into a family with significant disabilities, he shoulders the responsibility of caring for his blind father and locomotor-disabled mother. This case study delves into Rajan's life, highlighting his struggles as a primary caregiver, and advocating for a policy change to alleviate the financial burden on individuals like him.

Background

Rajan's father lost his vision completely at the age of 20, while his mother has locomotor disabilities. Despite these challenges, Rajan has persevered, working as an agricultural labourer to sustain his family. However, his responsibilities extend beyond earning a livelihood; he must also ensure his parents' well-being, often at the cost of his financial stability.

Challenges Faced

1. Economic Burden: Rajan's income is adversely impacted when his father requires medical attention or his mother needs assistance. He forfeits his daily wages to accompany his father to hospitals or procure medicines, exacerbating the financial strain on his already modest earnings.

2. Lack of Support: Existing government provisions fail to adequately address Rajan’s needs. While there are schemes aimed at assisting PwDs, no direct support mechanism for caregivers exists, leaving them to bear the brunt of caregiving responsibilities alone.

3. Social Stigma: In addition to the financial challenges, Rajan contends with societal perceptions that undervalue caregiving roles, often undermining the significance of his contribution to his family and community.

Proposed Solution

Direct Caregiver Allowance Payment: Recognising the critical role caregivers play in supporting individuals with disabilities, the government should implement a caregiver allowance scheme. Under this scheme, caregivers like Rajan would receive financial compensation directly from the government for their caregiving services.

Benefits

1. Financial Relief: Direct payment of caregiver allowances will alleviate the financial burden on individuals like Rajan, enabling them to meet their basic needs without sacrificing their earnings.

2. Recognition and Empowerment: By acknowledging the invaluable contributions of caregivers, the government can empower individuals like Rajan, affirming the importance of their role in society.

3. Enhanced Accessibility to Healthcare: With financial support in place, caregivers would no longer have to choose between earning a livelihood and ensuring access to essential healthcare services for their loved ones.

How frequently individuals interact with their caretakers every week?

Row Labels	Count of: How frequently do you interact with your caretaker on a weekly basis? आप साप्ताहिक आधार पर अपने देखभालकर्ता के साथ कितनी बार बातचीत करते हैं?
No / नहीं	0
(blank)	
Yes / हाँ	39
Multiple times a day	21
Daily	11
Few times a week	4
Once a week	1
Rarely	2
Total	39

This data indicates a high number of interactions with caregivers.

Case Study

Empowering Anushka: Navigating Spinal Muscular Atrophy Challenges

Anushka's story illuminates the resilience and determination of individuals living with Spinal Muscular Atrophy (SMA). Despite facing significant challenges, she pursues her dreams at IIT Kanpur with unwavering courage. However, Anushka's journey also underscores the need for comprehensive support systems to empower individuals with SMA and their caregivers. This case study explores the challenges Anushka and her family encounter and highlights the transformative impact of Cure SMA, an organisation dedicated to raising awareness and advocating for change.

Challenges Faced by Anushka

Living with SMA presents Anushka with daily obstacles, from basic tasks like transferring to more complex activities such as studying. Her reliance on external assistance, coupled withthe physical limitations imposed by the condition, underscores the necessity of specialised care and support.

The Struggle for Caregivers

The journey of Anushka's mother reflects the challenges caregivers face in finding reliable assistance. The difficulty in recruiting trained caregivers, compounded by instances of exploitation and blackmail, highlights the urgent need for structured caregiver programs and support networks.

Cure SMA: A Beacon of Support

Anushka's mother's initiative in founding Cure SMA demonstrates the power of advocacy and community-building. By providing vital information, support, and a platform for shared experiences, Cure SMA serves as a lifeline for individuals and families affected by SMA.

Recommendations for Improvement

1. Structured Caregiver Programs: Establish formalised caregiver training programs to ensure caregivers possess the necessary skills and understanding of SMA's challenges.

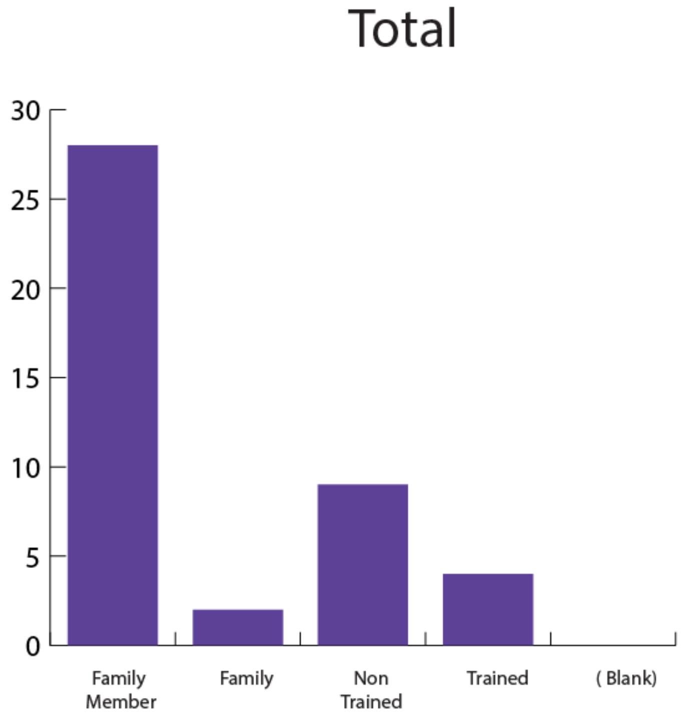
2. Strengthen Support Networks: Enhance online and offline support networks to facilitate resource sharing and mutual assistance among families and caregivers.

3. Advocacy for Policy Change: Advocate for policy changes that recognise and address the specific needs of individuals with SMA, including measures to facilitate caregiver recruitment and training.

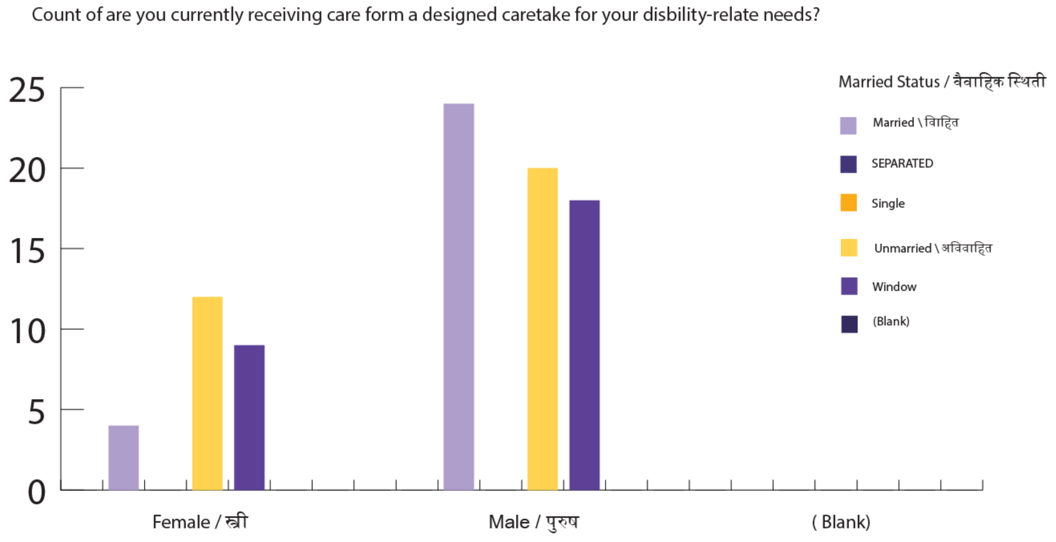
Conclusion

Anushka's journey underscores the resilience of individuals living with SMA and the transformative impact of organised advocacy and support initiatives. Through Cure SMA, Anushka's mother not only empowers her daughter but also contributes to a broader movement for positive change in the lives of those affected by SMA. By implementing structured caregiver programs, strengthening support networks, and advocating for policy change, we can create a more inclusive and supportive environment for individuals living with SMA and their families.

Here's the breakdown of who serves as the caretaker for individuals:

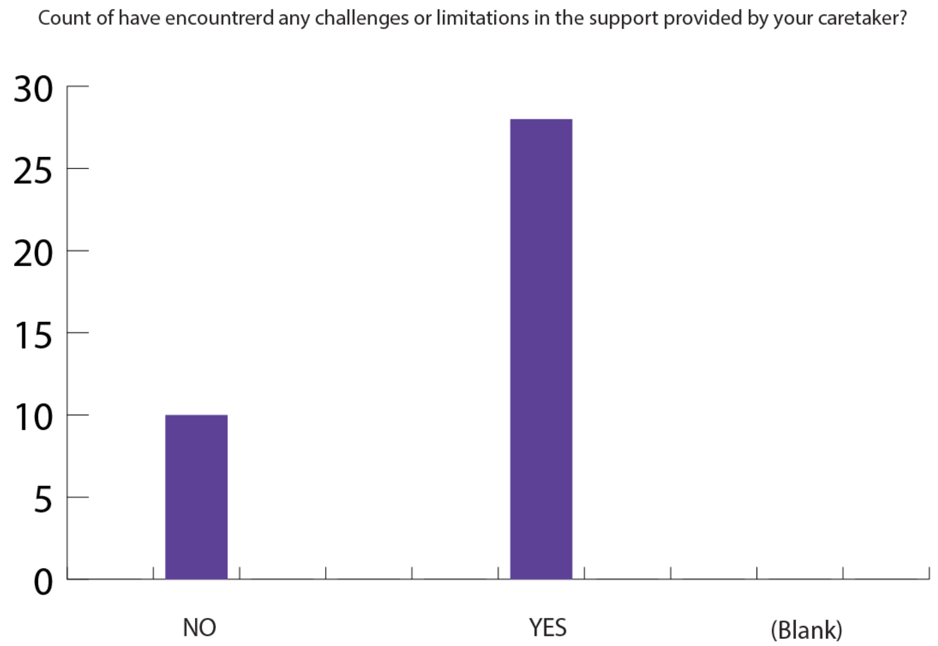


Women disproportionately shoulder the burden of unpaid care work. The statistics mentioned in the statement illustrate that Indian women spend more than five hours per day on unpaid care work, while men only spend 1.37 hours on average. because of unpaid caregiving work women went behind in participation of paid work by 16.1%. Equity in terms of gender is becoming significant and participation of men in caregiving should also promoted. The US recently unveiled the American families plan that classified “care” as essential infrastructure, marking a major shift in perception. Central and state government programs remain inadequate in catering the needs of caregivers. World economic forum (wef) that 40% of emerging job opportunities will be in the care sector highlights the growing significance of caregiving roles in the global economy. Factors contribute to this projected increase in job opportunities are-1) global shift in demographics, 2) changing social norms, 3) uptick in demand for trained caregivers.


Count of are you currently receiving care form a designed caretake for your disbility-relate needs?

Individuals currently receiving care from a designated caretaker for their disability-related based on marital status and gender

This image depicts a woman with a disability caused by polio, confronting daily challenges due to the exorbitant fees charged by NGOs and agencies for caregiving services. Other than going to her office, where she is aided by a driver, she relies entirely on her husband for mobility. If her husband is fatigued or unwell, she becomes confined to her home. Recently retired, she desires to engage in the disability sector and support others with disabilities. However, caregiving remains a significant obstacle as she requires assistance to travel anywhere beyond her workplace.



The count of individuals encountering challenges or limitations in the support provided by their caretaker

Row Labels	Count of: Have you encountered any challenges or limitations in the support provided by your caretaker?
No	10
Yes	29
(blank)	
Grand Total	39

Analysis

The chart reveals a critical insight into the effectiveness of caretaker support for individuals with disabilities. The higher number of Yes responses indicates a prevalent issue with the adequacy of support provided. This could be due to various factors such as lack of training, resources, or mismatched expectations between caretakers and those they support.

The relatively low number of No responses suggests that only a small fraction of individuals receive fully satisfactory support without any challenges or limitations.

Case Study

Navigating Challenges in Caregiving for Individuals with Muscular Dystrophy: A Case Study of Manav Goel

Introduction

Manav Goel, a 43-year-old individual living with muscular dystrophy in Haryana, faces numerous challenges in managing his condition and caregiving needs. Living with his sister, who also has muscular dystrophy, and their grandmother, who suffers from dementia, Manav relies on caregivers for support. However, he has encountered several difficulties, including issues with caregiver reliability, theft, and inappropriate behaviour. This case study explores Manav's experiences and highlights the importance of trustworthy and competent caregivers in providing adequate support for individuals with disabilities.

Background

Manav's life is marked by the complexities of living with muscular dystrophy, a progressive condition that affects his mobility and independence. Despite his challenges, Manav also cares for his sister and grandmother, both of whom have health issues. Dependence on caregivers becomes crucial for their day-to-day functioning, but Manav has faced setbacks due to the unreliability and misconduct of some caregivers.

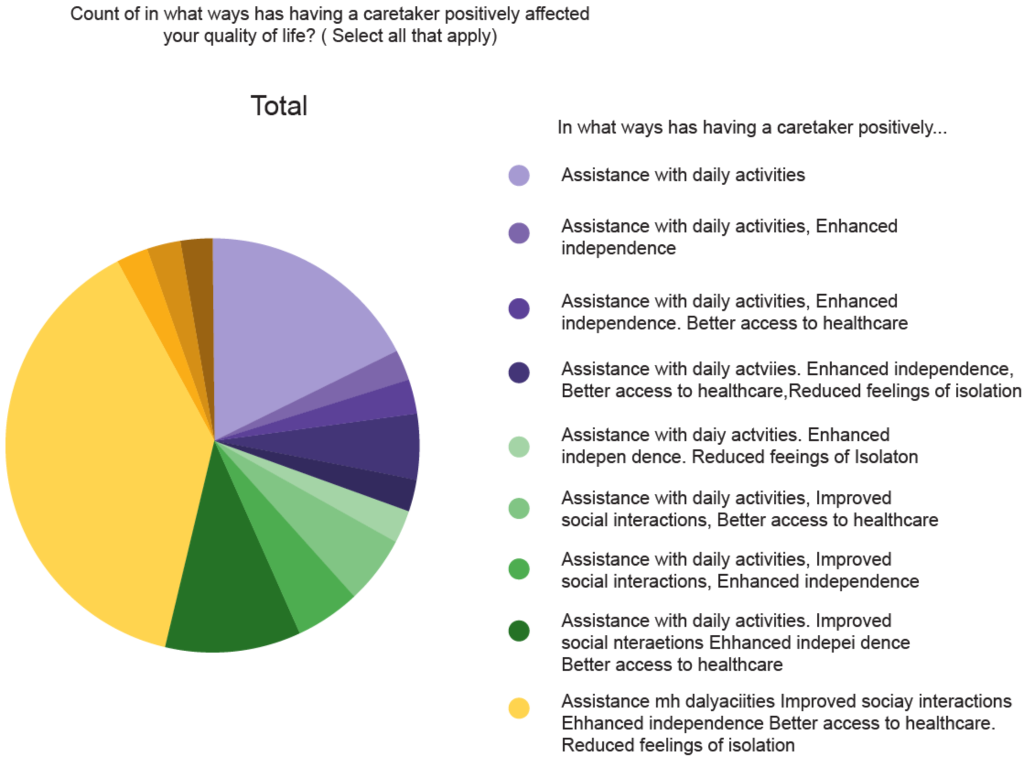
Challenges Faced

1. Reliability of Caregivers: Manav's experience with caregivers has been marred by unreliability, including issues such as lack of documentation, theft, and inappropriate behaviour, which compromise the quality of care and safety for him and his family.

2. Emotional Toll: Dealing with the challenges of finding and retaining trustworthy caregivers takes an emotional toll on Manav, exacerbating the stress and anxiety associated with managing his condition and caregiving responsibilities.

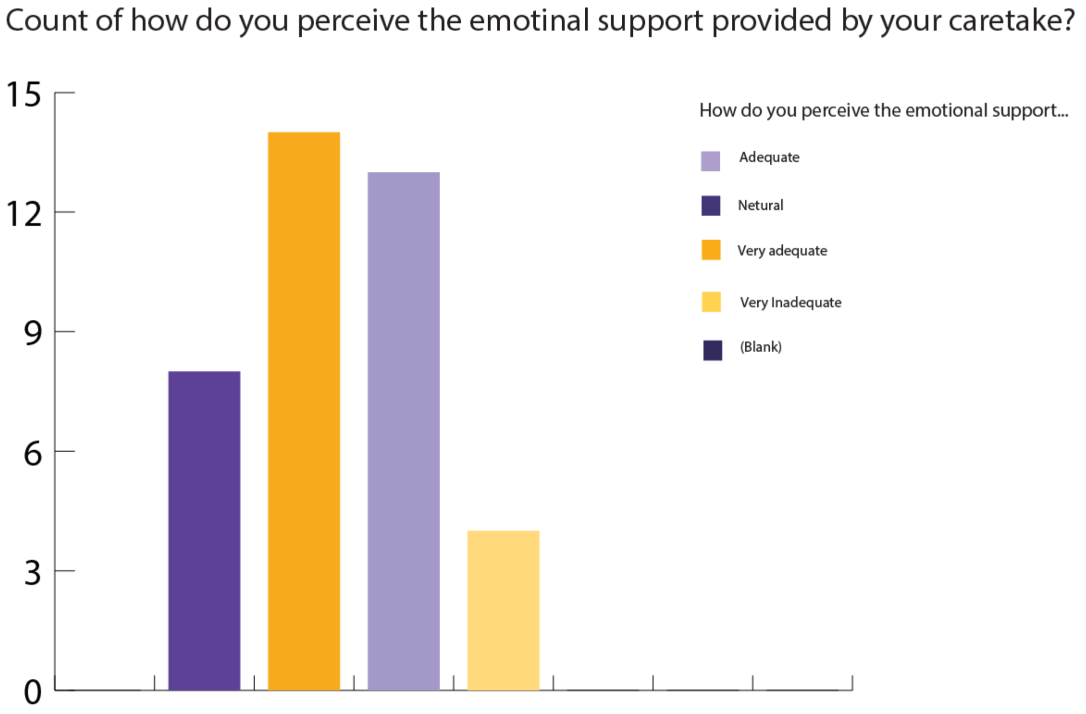
3.Need for Trustworthy Support: Manav emphasises the need for trustworthy caregivers who can provide competent and compassionate care, ensuring his well-being and dignity while respecting his autonomy and personal boundaries.

The data represents how having a caretaker has positively affected the individual’s quality of life.



This image portrays an elderly man who has developed disabilities in old age due to diabetes and high blood pressure. He relies on his family, particularly his wife who suffers from asthma, for everything from medication to food to healthcare access. Whenever they need to go anywhere, they must first ensure the availability of a driver who can assist with their care. As a retired government employee receiving a pension of around Rs 20-30,000, the exorbitant demands of NGOs and agencies for caregiving services, ranging from Rs 600 to Rs 1000 per day, pose a significant financial burden.

The data shows how individuals perceive the emotional support provided by their caretakers.



Ableism in caregiving needs to be shut

According to the 2001 census, over 21 million people - 2.1% of the Indian population - are disabled. Most PwDs live in rural areas, where it is often unknown that they even exist. The number of disabled people living in Uttar Pradesh (3.6 million), Bihar (1.9 million), and West Bengal (1.8 million) is higher than that of other states. Disablism as a culture, issues with infrastructure and design that are accessible, and policies that include people with disabilities are still controversial and, to some extent, widespread in India.

Wheelchair user Rahul Rawal who worked from home before the pandemic, candidly stated that COVID-19 was establishing a "level playing field." He added, "There has always been a problem with dependability for any kind of mobility." These days, I have more opportunities to interact thanks to online forums, and people recognising the importance of accessibility.”

Their opinions, in a sense, demonstrate how the pandemic has also revealed a silver lining and closed the gap between some individuals with disabilities and those without. However, there are issues in the denial of caregivers who help individuals interact, such as Sundari Siva Subbu, who said, "I am at home."

“My caregiver commutes from somewhere in a shared automobile. She could therefore infect me, which would make me vulnerable. We stopped her from coming because of the health risk, and my 63-year-old mother now assists me with the restroom, which is quite difficult for someone her age.” Her remarks, in a sense, gave a quick overview of family caregiving practices; however, given the variety of constraints and consequent dependability on nuclear families in urban India, more consideration should be given to these practices during a pandemic.

Beyond ageing family members, caregivers are increasingly needed due to the functional limitations of cerebral palsy, which is reported to be one of the leading causes of locomotor disability in India (NSSO 2002). Additionally, the number of nuclear families is growing.

Delhi-based Garima, 54, is her mother's primary caretaker. Her mother, 90, has dementia, a mental illness that impairs cognitive abilities like memory and reasoning and makes it difficult to carry out daily tasks. Garima is terrified of losing her mother even though she is sick of caring for her. She describes the day she almost died in early January as the scariest of her life.

However, Garima's mother is not always nervous and confused. She still stays busy; she likes to eat well, get her hair done, and visit coffee shops with Garima on Sundays. However, she requires a schedule, or else Garima becomes extremely nervous. Additionally, negative news has no place in this relationship.

Thousands of people in India are just like Garima. The impact of caregiving on carers is not given enough attention, despite the conversation around mental health having expanded to include more psychiatric disorders like dementia, schizophrenia, bipolar disorder, and more common issues like anxiety and depression.

The stress experienced by the person providing care for a chronically ill or disabled person is known as the caregiver burden. Stress can manifest in various ways, including financial, emotional, and psychological, to mention a few. Research has indicated a notable prevalence of anxiety and depression among individuals who provide care for individuals with illnesses like dementia. In addition to the psychological and emotional strain of providing care, physical health problems like insomnia and hypertension can arise.[11]

What to do to Intervene in the Caregiving Sector?

Caregivers play a crucial role in supporting individuals with disabilities, and their efforts are vital for the well-being of those they care for. Here are a few key considerations and potential areas for improvement:

1.Data and Research: Conducting detailed studies and reviews on the impact of caregiving on individuals, families, and national productivity is essential. This data can provide insights into the challenges faced by caregivers, including lost work hours and productivity, and can serve as a foundation for informed policy decisions.

2.Legal and Civic Support Systems: Evaluating and potentially revising existing legal and civic support systems for caregivers can help ensure they have the necessary protections and resources. This may involve creating specific policies or amendments to existing laws to address the needs and challenges caregivers face.

3.Comparison with International Standards: Comparing caregiver support systems in India with other nations can provide valuable benchmarks. This analysis can help identify best practices and innovative solutions implemented elsewhere that could be adapted to the Indian context.

4.Government Initiatives: Advocating the establishment of a dedicated funding agency or department under the Government of India to address the needs of caregivers could be a significant step. This agency could focus on developing and implementing policies that support caregivers, including financial assistance, training programs, and mental health resources.

5.Public Awareness and Advocacy: Raising awareness about the challenges faced by caregivers and advocating for their rights and support can garner public and governmental attention. This can lead to a more supportive environment and policy changes.

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[11] per perspectives-jdmc.in

6.Collaboration with NGOs and Community Organisations: Collaborating with NGOs and community-based organisations that work with caregivers and individuals with disabilities can provide valuable insights and enhance the effectiveness of support programs.

Allowing elderly care seekers to choose a family caregiver with support from the welfare states suggests a person-centred approach to caregiving. This model emphasises the importance of personal choice and familial relationships in providing care for the elderly.

Some key points that can be inferred from this approach include:

1.Choice and Autonomy: The emphasis on allowing the elderly care seeker to choose their family caregiver reflects a commitment to individual choice and autonomy.This approach recognises that individuals may have varying preferences and comfort levels with specific caregivers, including family members.

2.Welfare State Support: The involvement of welfare states in supporting family caregivers indicates a recognition of the societal importance of caregiving. Providing support to family caregivers acknowledges their role in the overall healthcare system and the well-being of elderly individuals.

3.Policy Flexibility: This model suggests a level of flexibility in policies that accommodates the diverse needs of elderly individuals and their families. Such flexibility can contribute to a more adaptable and responsive caregiving system.

12 Secondary Study

Unveiling the Well-being: A Cross-sectional Study on the Quality of Life of Caregivers Supporting Autistic Children and Adolescents in Health Facilities of Lucknow City, Uttar Pradesh

The sample included 90 principal caregivers (aged < 60 years) of autistic children and adolescents aged 3–19 years and diagnosed with autism, attending government and private health facilities providing treatment for autism in Lucknow.

Results

The quality of life of principal caregivers was found to be influenced most in the physical health domain (with the lowest score). The predictors of the quality of life of principal caregivers were the type of family and knowledge regarding the child's problem.

Among the 90 caregivers in this study, 26 caregivers belonged to districts of Uttar Pradesh other than Lucknow or adjoining states (including Madhya Pradesh and Orissa). Among the caregivers from districts other than Lucknow, 17.8% stayed in Lucknow for their child's treatment. The majority (87.8%) of the principal caregivers were mothers, and despite 77.8% being graduates or postgraduates, 73.3% were unemployed. The caregivers who knew about the child's problem, autism, and the care modalities of autism had statistically significant better environmental health as compared to caregivers who did not know.

Among the caregivers, ~ 77% were highly educated (graduate or postgraduate). Despite this higher education, they preferred to be unemployed as one of the parents had to constantly look after the child. The out-of-pocket expenditure due to the nonworking parent poses a problem for the economy. Among the four domains of quality of life, the lowest median score (thus the poorest quality of life) was found in the physical health domain followed by the psychological health domain.[12]

Court Cases
Court cases in which the primary caregiver had to fight for their caregiving rights and for securing their disabled parents and siblings along with securing and safeguarding their jobs.

VIVEKANANDHAN N V. EMPLOYEES STATE INSURANCE CORPORATION

1. Hon'ble Dr. K.B. Suresh, Member (J) Applicant claims that his daughter is 100% disabled and therefore coming under the umbrella of the DOPT circular issued in this regard by the Government of India. As a caregiver, certain benefits must be granted to the caregiver in matters of transfer. The respondents submit that there were two promotees and only one vacant promotional post, therefore, one lady who will retire on 31st May 2019 was posted there and the applicant was moved out but practically now if the applicant can be accommodated for one more month, the applicant can be retained here itself unless there is some other person who is better qualified to come to Bangalore. With this reservation and liberty, we will now permit the applicant to continue in Bangalore in the original post at Bangalore itself following the Government of India directions but will also allow the respondents to examine the matter afresh if it appears that there are other persons better qualified than the applicant to Bangalore.

2. The applicant will be accommodated till the 31st of May and then accommodated in the vacant position unless better-qualified persons are available. The applicant can have the promotional post on 1st June.

3. The OA is disposed of as above. No order as to costs. [13]

Munmum Sen Petitioner(s) v. State Of Tripura And Another (s).

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[12] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6625252/

[13] https://www.casemine.com/judgement/in/5d82356a4a9326476b5f68e5

1. The petitioner contends that both her husband and son are physically disabled. They stay in Agartala. She submitted a representation to the authority concerned to transfer her to Agartala as she is their only caregiver, and comes within the purview of the notifications dated 8.10.2018 and 15.11.2021. When the matter was taken up, Mr. M. Debbarma, the learned Addl. G.A. placed an order dated 09.01.2023 before this court whereby and whereunder the request of the petitioner has been acceded to and she has been transferred to Old Central Jail Quarter Complex, Dhaleswar, Agartala under Bhati Aboynagar UPHC from her earlier place of posting at Purathal Rajnagar Health Sub- Centre, Bishalgarh, Sepahijala district. Thus, the petitioner's request has been addressed. Ms. A. Debnath, Ld. counsel for the petitioner also submits that she has no grievance in view of the order dated 9.01.2023.

2. In view of this, no further order is necessary by this Court.

3. Accordingly, the instant writ petition stands disposed. [14]

13 Case Studies

1. Tulika Roy is a person with an intellectual disability autism and a delayed milestone. She is 45 years old and dependent on her parents for every task. Her parents are worried about who will take care of her after their death. Her father admitted her to different schools for almost 30 years but no significant progress can be seen in her behaviour. He wants to live in Lucknow but in the search for an appropriate school, he must move from one city to another.

Her daily assistance includes the person who is a household worker in their home paid Rs 5000-6000 monthly. She is untrained and unable to understand Tulika's behaviour, and her old mother must help her with daily tasks such as bathing, food and eating.

Currently, Tulika is at Rainbow School for the Differently Abled, where she is slightly responsive and doing exercises as instructed but at her age, it is not possible to expect a great improvement.

The mother is unable to go anywhere leaving Tulika alone. The parents are unable to attend social functions. Her father has demanded that the government and private sector initiate a project for such persons to be looked after, after the death of the parents. According to him, the schools have no trained caregivers. There is no emotional support which is much needed for the development of children with autism. Further, trained caregivers who can understand and tackle the behaviour of children with intellectual disabilities is the need of the hour and a residential setup with facilities-trained caregivers is a matter of priority.

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[14] https://www.casemine.com/judgement/in/63c82daf11c0173e31edd521

2. Navigating Challenges: The Journey of Ishan with Cerebral Palsy

Introduction: Ishan, a 22-year-old BA final-year student, faces the daily struggles of living with cerebral palsy. His dependence on his mother for basic needs and the challenges of mobility present significant obstacles in his daily life. Despite these challenges, Ishan remains hopeful, and supported by his family, yet recognises the need for more inclusive infrastructure and support systems to facilitate his independence and participation in society.

Background: Diagnosed with cerebral palsy at birth, Ishan's condition has presented ongoing challenges in his life. As he approaches the final year of his undergraduate studies, Ishan finds himself dependent on his mother for essential tasks, including washroom assistance. Additionally, the lack of available caregivers often limits his ability to participate in important events and outings.

Challenges Faced

Dependency on Caregivers: Ishan's reliance on his mother for washroom assistance and the need for multiple individuals to assist him when going out highlights the limitations imposed by his disability. This dependency affects his autonomy and hinders his ability to engage fully in various activities.

Accessibility Barriers: Ishan's mobility limitations necessitate the assistance of multiple individuals and specialised transportation arrangements when going outdoors. The lack of accessibility features in public spaces such as theatres and malls further compounds his challenges, restricting his freedom of movement and participation in social activities.

Social Isolation: The inability to attend important events and outings due to the unavailability of caregivers exacerbates Ishan's sense of social isolation. This isolation can lead to feelings of loneliness and exclusion, impacting his mental well-being and overall quality of life.

Support System

Family Support: Ishan finds solace and support in his family, particularly his mother, who serves as his primary caregiver. Their unwavering support and encouragement provide him with the strength and resilience to navigate the challenges posed by his disability.

3. Resilience in Adversity: Prakash's Journey Through Paralysis

Introduction

Prakash's life took an unexpected turn when a brain haemorrhage left him paralysed two years ago. Despite the immense challenges posed by his disability, Prakash has shown remarkable resilience and determination in navigating through his circumstances. This case study explores

Prakash's journey, shedding light on the obstacles he faces, the support system that sustains him, and his aspirations for the future.

Background

Prakash, a 37-year-old resident of Delhi, India, was leading a normal life until a medical emergency altered his trajectory. The sudden onset of paralysis following a brain haemorrhage rendered him dependent on others for basic tasks, profoundly affecting his physical, emotional, and financial well-being.

Challenges Faced

1. Physical Limitations: Paralysis confined Prakash to a wheelchair, posing significant obstacles to everyday activities such as dressing and bathing, and restricting his mobility.

2. Social Isolation: Prakash's inability to participate in social events due to the lack of a caregiver contributed to feelings of loneliness and disconnection from the community.

3. Employment Struggles: Limited education and mobility hindered Prakash's ability to secure gainful employment, exacerbating his financial hardships and sense of worthlessness.

Support System

1. Family: Prakash's wife and children have been a pillar of strength, offering unwavering support and assistance in his daily life.

2. Financial Assistance: Prakash relies on support from his parents and occasional credit to meet his financial needs, highlighting the strain his disability places on his family's resources.

Aspirations and Future Outlook

Despite facing numerous challenges, Prakash remains determined to rebuild his life. He aspires to gain independence, pursue further education or vocational training, and secure meaningful employment aligned with his abilities and interests.

Conclusion

Prakash's journey exemplifies the resilience of the human spirit in the face of adversity. Despite grappling with physical limitations and societal barriers, he continues to persevere, buoyed by the support of his family and community. His story reminds us of the importance of empathy, inclusivity, and robust support systems in enabling individuals with disabilities to lead dignified and fulfilling lives.

14 Secondary Survey Of Caregiver Services In Developed Countries

United States

The number of family caregivers available for caregiving is expected to decline from 7:1 in 2010 to 4:1 by 2030, There are approximately 2.9 million family caregivers of individuals with ID/DD in the U.S. Established in 2000, the NFCSP provides grants to states and territories, based on their share of the population age 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible.[15]

Australia

The government provides additional support, including payments to support carers and the people they care for. At the Commonwealth level, a National Carer Recognition Framework encompasses the Carer Recognition Act 2010 and the National Carer Strategy. The Act includes a definition of carer, establishes the Statement for Australia’s Carers, outlines different parties’ responsibilities in respect of the Statement and sets up reporting and consultation arrangements for certain Australian Public Service agencies. Australia is one country that identifies caregiver support as the third integral component of formal support in addition to community care and residential care.

In Japan, Spain, the United Kingdom and some northern European countries, municipalities oversee organising respite care, particularly in the case of day-care and in-home respite, which leads to large local disparities in access and availability. [16]

Countries that have provided direct financial aid to help defray the costs of care include Australia (which provides benefits such as a Caregiver Allowance and Caregiver Payment), and Germany, which allows family caregivers to claim incurred expenses associated with hiring help to care for a household member (Montgomery and Feinberg 2003). Such financial aid given to family caregivers could alleviate their financial burden and provide recognition for their contributions.

There is a need for government to design family policies that help families better manage work and family care responsibilities, be paid for taking leave to fulfil family caregiving responsibilities and be subsidised for child care and older adult care.

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[15] www.ncbi.nlm.nih.gov

[16] www.alrc.gov.au

15 Recommendations for Improving Caregiver Structure

1. Establishment of a Dedicated Sub-Ministry: The government should create a dedicated sub-ministry focused on caregiving to oversee and coordinate policies, programs, and services for individuals with disabilities and their caregivers.

2. Strengthening of the National Trust: The National Trust, tasked with supporting individuals with disabilities, should prioritise caregiving initiatives and ensure the effective implementation of support programs.

3. Corporate Social Responsibility Engagement: Private players should allocate CSR funds towards initiatives supporting caregivers, including training programs, financial assistance, and awareness campaigns.

4. Subsidies for Affordability: The government should provide subsidies or financial assistance to families who cannot afford caregiving services, ensuring accessibility and affordability for all individuals with disabilities.

5. Sensitisation and Awareness Campaigns: The government should conduct sensitisation and awareness sessions to destigmatise caregiving and promote it as a respectable profession, encouraging more individuals to pursue careers in caregiving.

6. On-Demand Caregiving Services: Like on-demand food delivery services, caregiving services should be accessible with a single call, ensuring continuous support for individuals with disabilities even if one caregiver is unavailable.

7. Tailored Training for Different Disabilities: Caregivers should receive specialised training based on the specific needs of individuals with different disabilities, such as intellectual and locomotor disabilities.

8. Overseeing NGOs and Agencies: The government should regulate and monitor NGOs and agencies providing caregiving services to prevent exploitation or mistreatment of individuals with disabilities by ensuring transparency and accountability in their operations.

By implementing these recommendations, the government and private players can create a robust caregiver structure that ensures quality care, support, and dignity for individuals with disabilities and their caregivers.

16 Annexures

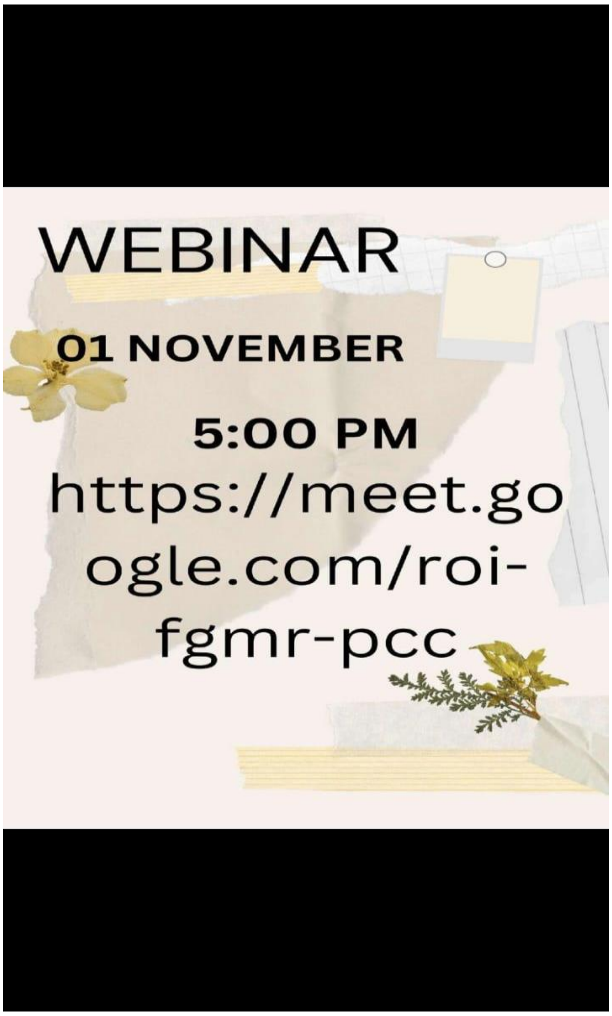
1. Pictures of work done till now

2. Webinar sessions

Importance of Caregiver in the life of Person with SMA

SMA Awareness Month

Date & Time: 29th August, 6pm IST



भारत में विकलांग व्यक्तियों की देखभाल करने वालों की महत्वपूर्ण भूमिका

भारत में विकलांग व्यक्तियों के अधिकार अधिनियम, 2016, एक देखभालकर्ता को ऐसे व्यक्ति के रूप में परिभाषित करता है जो किसी विकलांग व्यक्ति को भुगतान या अवैतनिक देखभाल, सहायता या सहायता प्रदान करता है। 2018 के राष्ट्रीय नमूना सर्वेक्षण (एनएसएस) के अनुसार, लगभग 62.02% विकलांग व्यक्ति (पीडब्ल्यूडी) देखभाल करने वालों पर निर्भर हैं, जबकि 0.26% को इन सेवाओं की आवश्यकता होती है, लेकिन वे इन सेवाओं तक नहीं पहुंच पाते हैं।

परिवार के सदस्य, विशेष रूप से पति-पत्नी और माताएँ, अधिकांश देखभाल प्रदान करते हैं, जिसमें 65% से अधिक देखभाल करने वाली महिलाएँ हैं। जैसे-जैसे भारत में वृद्ध लोगों की जीवन प्रत्याशा बढ़ रही है, दीर्घकालिक देखभाल की मांग भी बढ़ रही है। बदलते रोग पैटर्न, चिकित्सा प्रगति, शहरीकरण और आर्थिक विकास जैसे कारक इस प्रवृत्ति में योगदान करते हैं। स्पाइनल मस्कुलर एट्रोफी, मस्कुलर डिस्ट्रॉफी और सेरेब्रल पाल्सी जैसी स्थितियों वाले व्यक्तियों के लिए देखभाल करने वालों तक पहुंच आवश्यक है, जिन्हें दैनिक कार्यों के लिए पूर्णकालिक सहायता की आवश्यकता होती है।

गंभीर आवश्यकता के बावजूद, पूर्णकालिक सहायता की आवश्यकता वाले लोगों के सामने आने वाली चुनौतियों के बारे में जागरूकता कम है। अनौपचारिक देखभाल, अक्सर सह-निवासी परिवार के सदस्यों द्वारा, भारत में देखभाल परिदृश्य पर हावी है। हालाँकि, इस प्रकार की देखभाल औपचारिक स्वास्थ्य सेवाओं से अलग है और अक्सर अवैतनिक होती है। देखभाल करने वाले अक्सर देखभाल प्रदान करने के लिए अपने स्वयं के काम में कटौती करते हैं, और उनके मानसिक स्वास्थ्य और कल्याण को अक्सर नजरअंदाज कर दिया जाता है। यह धारणा कि परिवार की उपस्थिति पर्याप्त देखभाल सुनिश्चित करती है, त्रुटिपूर्ण है, जैसा कि वृन्दावन जैसे मंदिर शहरों में वृद्ध, बीमार या विकलांग महिलाओं को छोड़ दिए जाने से प्रमाणित होता है। 2012 में सुप्रीम कोर्ट ने इन महिलाओं की पहचान और जांच का आदेश दिया, लेकिन प्रक्रिया अधूरी है। एक महत्वपूर्ण विकलांग आबादी के साथ, देखभाल संरचनाओं और प्रशिक्षण कार्यक्रमों को विकसित करना आवश्यक है जो विकलांग लोगों की विविध आवश्यकताओं को संबोधित करते हैं।

निजी और सरकारी क्षेत्रों, विकलांगता संगठनों, स्वास्थ्य देखभाल पेशेवरों और शिक्षकों के बीच सहयोग आवश्यक है। हालाँकि, चुनौतियाँ अभी भी बनी हुई हैं, जैसे कम वेतन, खराब नौकरी धारणा, देखभाल करने वालों के लिए अपर्याप्त शिक्षा और प्रशिक्षण के अवसर और देखभाल करने वाली भूमिकाओं का सामाजिक अवमूल्यन। स्थिर रोजगार स्थितियों और प्रतिस्पर्धी वेतन की कमी के कारण भारत में देखभाल करने वालों की कमी बढ़ गई है, जिससे व्यक्ति कहीं और बेहतर अवसर तलाशने के लिए प्रेरित हो रहे हैं। सामाजिक धारणाओं को बदलना और देखभाल को एक सम्मानजनक और मूल्यवान पेशे के रूप में मान्यता देना महत्वपूर्ण है। अंत में, देखभाल करने वालों की जरूरतों को संबोधित करना और पर्याप्त सहायता और प्रशिक्षण प्रदान करना यह सुनिश्चित करने के लिए आवश्यक है कि भारत में विकलांग व्यक्तियों को उच्च गुणवत्ता वाली देखभाल और सहायता मिले जिसके वे हकदार हैं।

Priya Srivastava

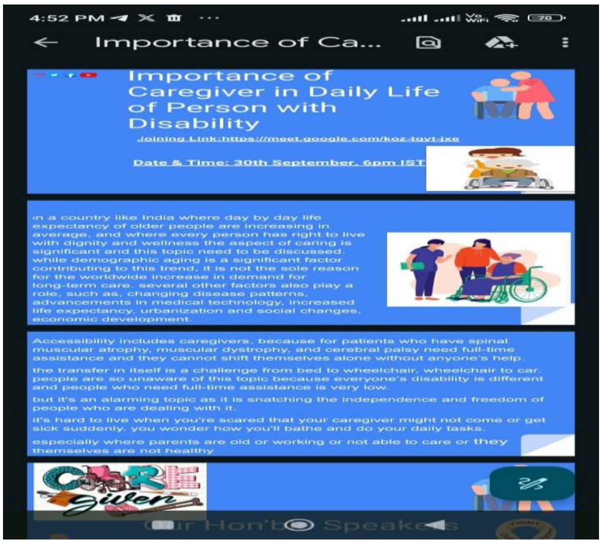
I had a productive meeting with the Deputy Commissioner and the Commissioner of... see more

WEBINAR- IMPORTANCE OF CAREGIVING IN CHILDREN WITH DOWN SYNDROME
24/03/2024, TIME-6:00PM
Google meet link
https://meet.google.com/kiy-vgrv-rpy

Dr. Anshika Pathak
Physiotherapist

Neha Tiwari
Audiologist & Speech Language Pathologist

organized by-INDIANWHEELCHAIRGIRL



Importance of Caregiver in Daily Life of Person with Disability

Joining Link:https://meet.google.com/koz-tqyt-jxe

Date & Time: 30th September, 6pm IST

in a country like India where day by day life expectancy of older people are increasing in average, and where every person has right to live with dignity and wellness the aspect of caring is significant and this topic need to be discussed. while demographic aging is a significant factor contributing to this trend, it is not the sole reason for the worldwide increase in demand for long-term care. several other factors also play a role, such as, changing disease patterns, advancements in medical technology, increased life expectancy, urbanization and social changes, economic development.

Accessibility includes caregivers, because for patients who have spinal muscular atrophy, muscular dystrophy, and cerebral palsy need full-time assistance and they cannot shift themselves alone without anyone's help.

the transfer in itself is a challenge from bed to wheelchair, wheelchair to car. people are so unaware of this topic because everyone's disability is different and people who need full-time assistance is very low.

but it's an alarming topic as it is snatching the independence and freedom of people who are dealing with it.

it's hard to live when you're scared that your caregiver might not come or get sick suddenly. you wonder how you'll bathe and do your daily tasks.

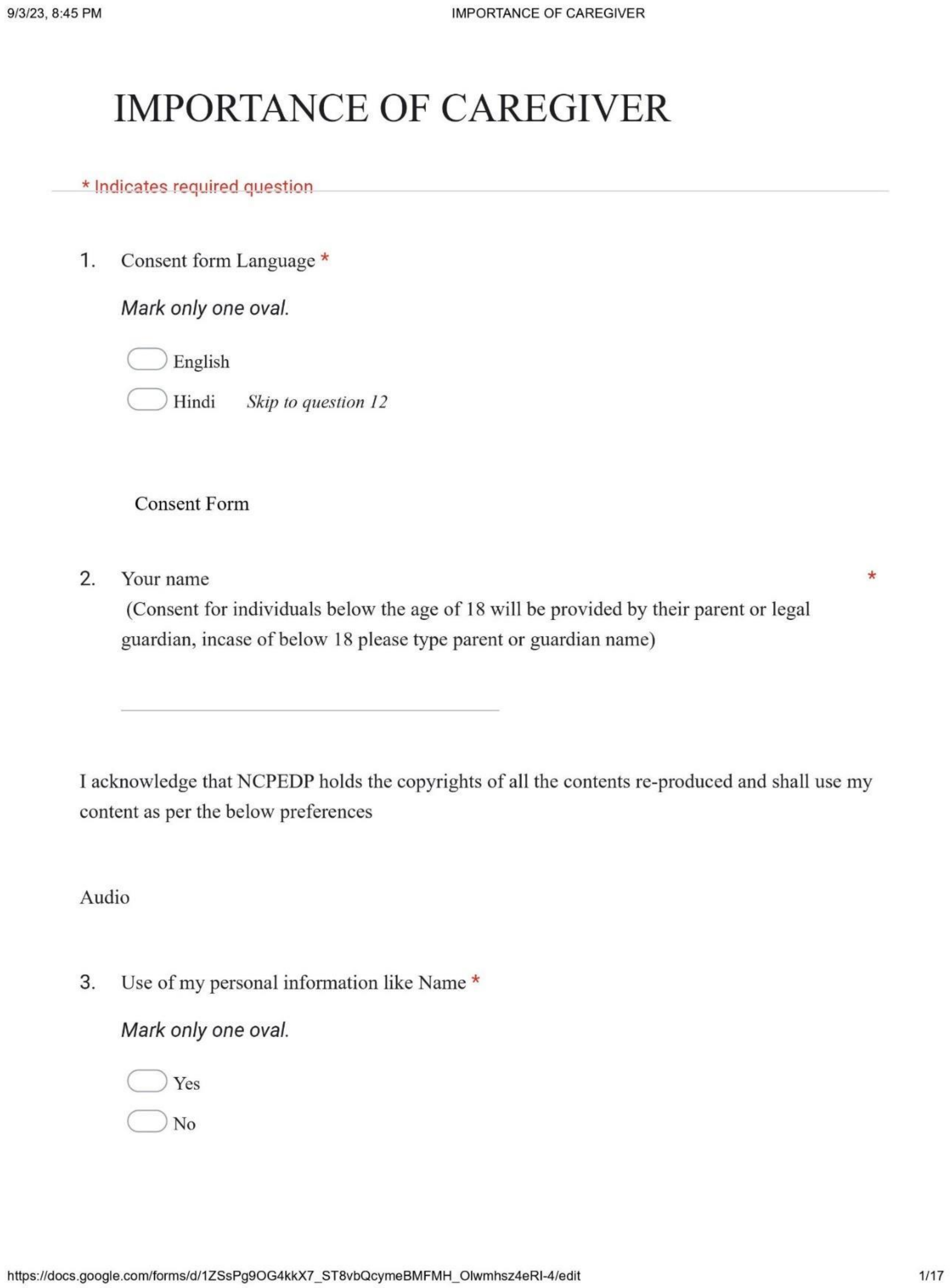
especially where parents are old or working or not able to care or they themselves are not healthy

जीने के अधिकार के संदर्भ में देखभाल का महत्व

संवाददाता

निःसंदेह, भारत जैसे देश में जहां वृद्ध लोगों की औसत जीवन प्रत्याशा दिन–ब–दिन बढ़ रही है, वहां प्रत्येक व्यक्ति के गरिमा और कल्याण के साथ जीने के अधिकार के संदर्भ में देखभाल का महत्व बहुत अधिक है और इस विषय पर चर्चा की जानी चाहिए। यद्यपि जनसांख्यिकीय उम्र बढ़ने की यह प्रवृत्ति एक महत्वपूर्ण कारक है, यह एकमात्र कारण नहीं है जिसके कारण लंबे समय तक देखभाल की मांग दुनिया भर में बढ़ रही है। कई अन्य कारक भी महत्वपूर्ण भूमिका निभाते हैं जैसे कि बदलते रोग पैटर्न, चिकित्सा प्रौद्योगिकी में प्रगति, जीवन प्रत्याशा में वृद्धि, शहरीकरण और सामाजिक परिवर्तन, और आर्थिक विकास। दृष्टिगतता (accessibility) में देखभाल करने वालों (caregivers) का समावेश भी होना चाहिए, क्योंकि जिन रोगियों को स्पाइनल मस्कुलर एट्रोफी, मस्कुलर डिस्ट्रॉफी और सेरेब्रल पाल्सी जैसी बीमारियां हैं, उन्हें पूरे समय सहायता की आवश्यकता होती है और वे किसी की मदद के बिना खुद को स्थानांतरित नहीं कर सकते। बिस्तर से व्हीलचेयर तक, व्हीलचेयर से कार तक स्थानांतरित करना ही एक चुनौती है। इस विषय पर लोग इतने अनजान हैं क्योंकि हर किसी की विकलांगता अलग–अलग होती है और जिन लोगों को पूरे समय सहायता की आवश्यकता होती है, उनकी संख्या बहुत कम है। लेकिन यह एक गंभीर मुद्दा है क्योंकि यह उन लोगों की स्वतंत्रता और आजादी को छीन रहा है जो इसका सामना कर रहे हैं। जीवन कठिन हो जाता है जब आप डरते हैं कि आपका देखभालकर्ता नहीं आ सकता है या अचानक बीमार हो सकता है। आप सोचते हैं कि आप कैसे स्नान करेंगे और अपनी दैनिक गतिविधियां कैसे करेंगे। विशेषकर जहां माता–पिता वृद्ध हैं, कामकाजी हैं या खुद ही स्वस्थ नहीं हैं और देखभाल करने में सक्षम नहीं हैं। लोगों के मन में यह एक अनादरपूर्ण काम माना जाता है और वे किसी का व्हीलचेयर नहीं चलाना चाहते या यह उनके लिए शर्मनाक है। विकलांगों की देखभाल के लिए लोग अत्यधिक कीमतों की मांग करते हैं, जो बहुत ही महंगी होती हैं। इस मुद्दे पर समाज में जागरूकता फैलाना और देखभाल करने वालों की उचित ट्रेनिंग और वेतन संरचना को सुनिश्चित करना महत्वपूर्ण है ताकि हर व्यक्ति गरिमा के साथ जीवन जी सके।

3. Consent and Google questionnaire form



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IMPORTANCE OF CAREGIVER

* Indicates required question

1. Consent form Language *

Mark only one oval.

○ English
○ Hindi *Skip to question 12*

Consent Form

2. Your name *
(Consent for individuals below the age of 18 will be provided by their parent or legal guardian, incase of below 18 please type parent or guardian name)

____

I acknowledge that NCPEDP holds the copyrights of all the contents re-produced and shall use my content as per the below preferences

Audio

3. Use of my personal information like Name *

Mark only one oval.

○ Yes
○ No

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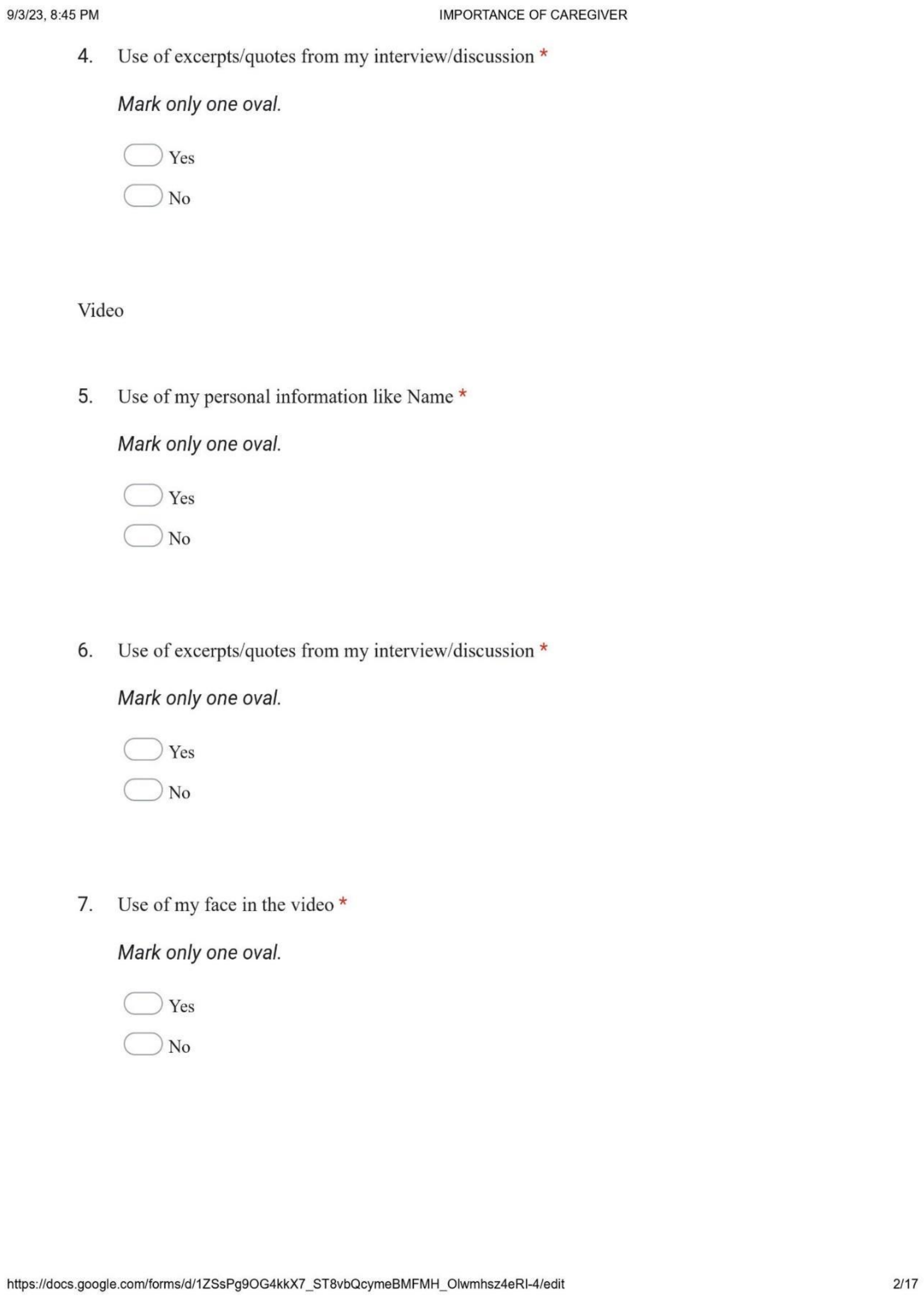


4. Use of excerpts/quotes from my interview/discussion *

Mark only one oval.

○ Yes
○ No

Video

5. Use of my personal information like Name *

Mark only one oval.

○ Yes
○ No

6. Use of excerpts/quotes from my interview/discussion *

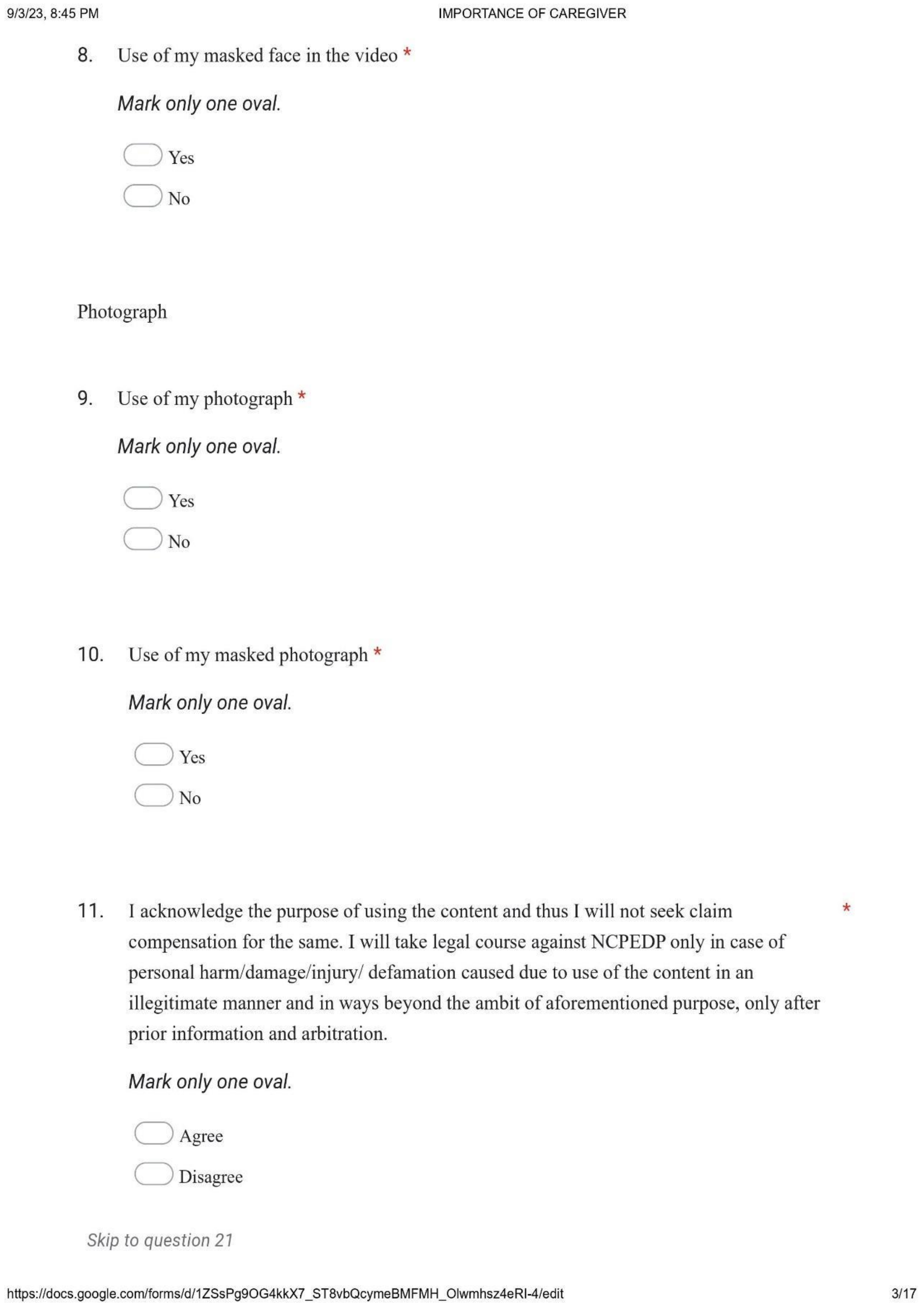
Mark only one oval.

○ Yes
○ No

7. Use of my face in the video *

Mark only one oval.

○ Yes
○ No



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8. Use of my masked face in the video *

Mark only one oval.

○ Yes
○ No

Photograph

9. Use of my photograph *

Mark only one oval.

○ Yes
○ No

10. Use of my masked photograph *

Mark only one oval.

○ Yes
○ No

11. I acknowledge the purpose of using the content and thus I will not seek claim compensation for the same. I will take legal course against NCPEDP only in case of personal harm/damage/injury/ defamation caused due to use of the content in an illegitimate manner and in ways beyond the ambit of aforementioned purpose, only after prior information and arbitration. *

Mark only one oval.

○ Agree
○ Disagree

Skip to question 21

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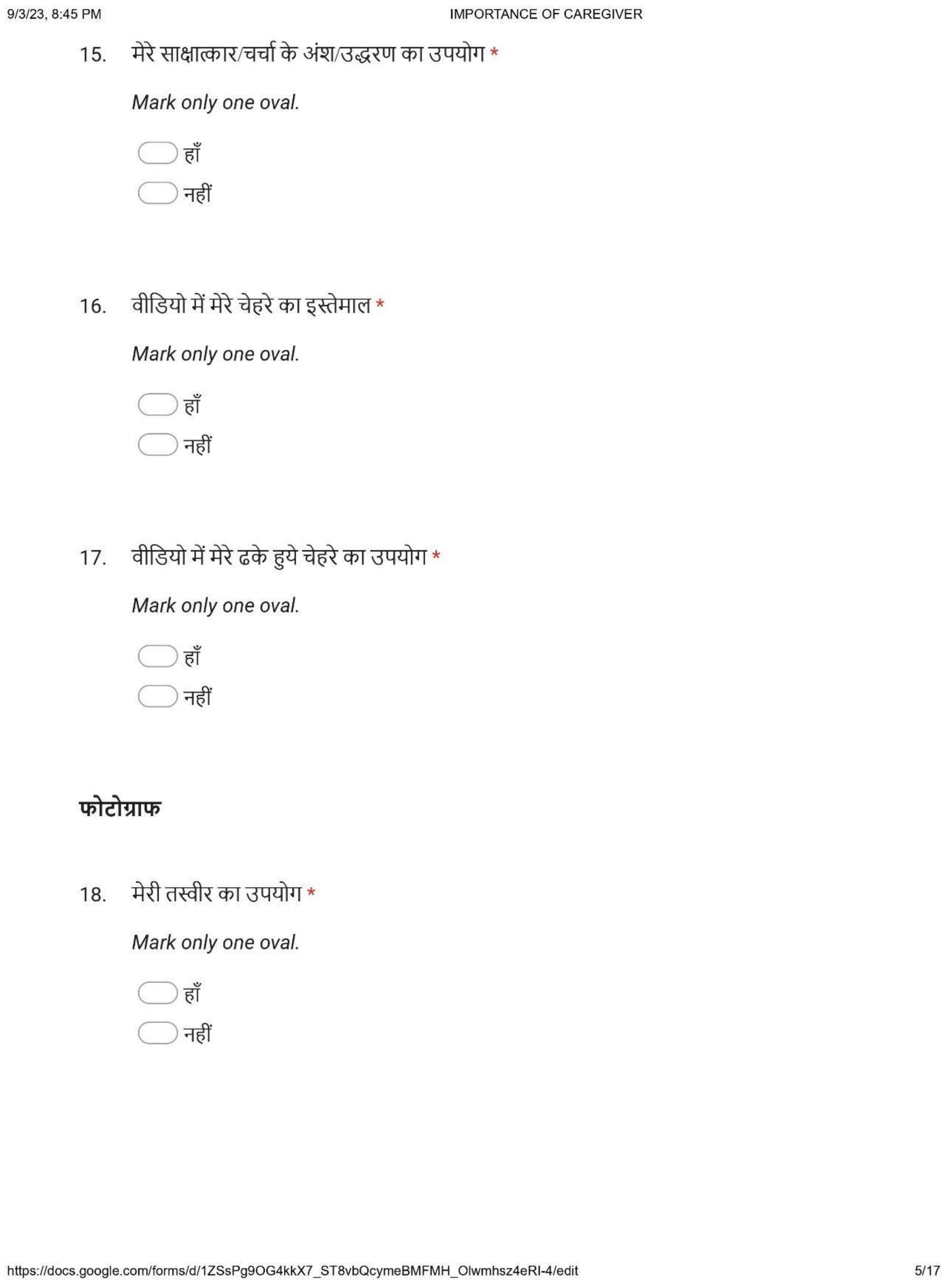

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15. मेरे साक्षात्कार/चर्चा के अंश/उद्धरण का उपयोग *

Mark only one oval.

○ हाँ
○ नहीं

16. वीडियो में मेरे चेहरे का इस्तेमाल *

Mark only one oval.

○ हाँ
○ नहीं

17. वीडियो में मेरे ढके हुये चेहरे का उपयोग *

Mark only one oval.

○ हाँ
○ नहीं

फोटोग्राफ

18. मेरी तस्वीर का उपयोग *

Mark only one oval.

○ हाँ
○ नहीं

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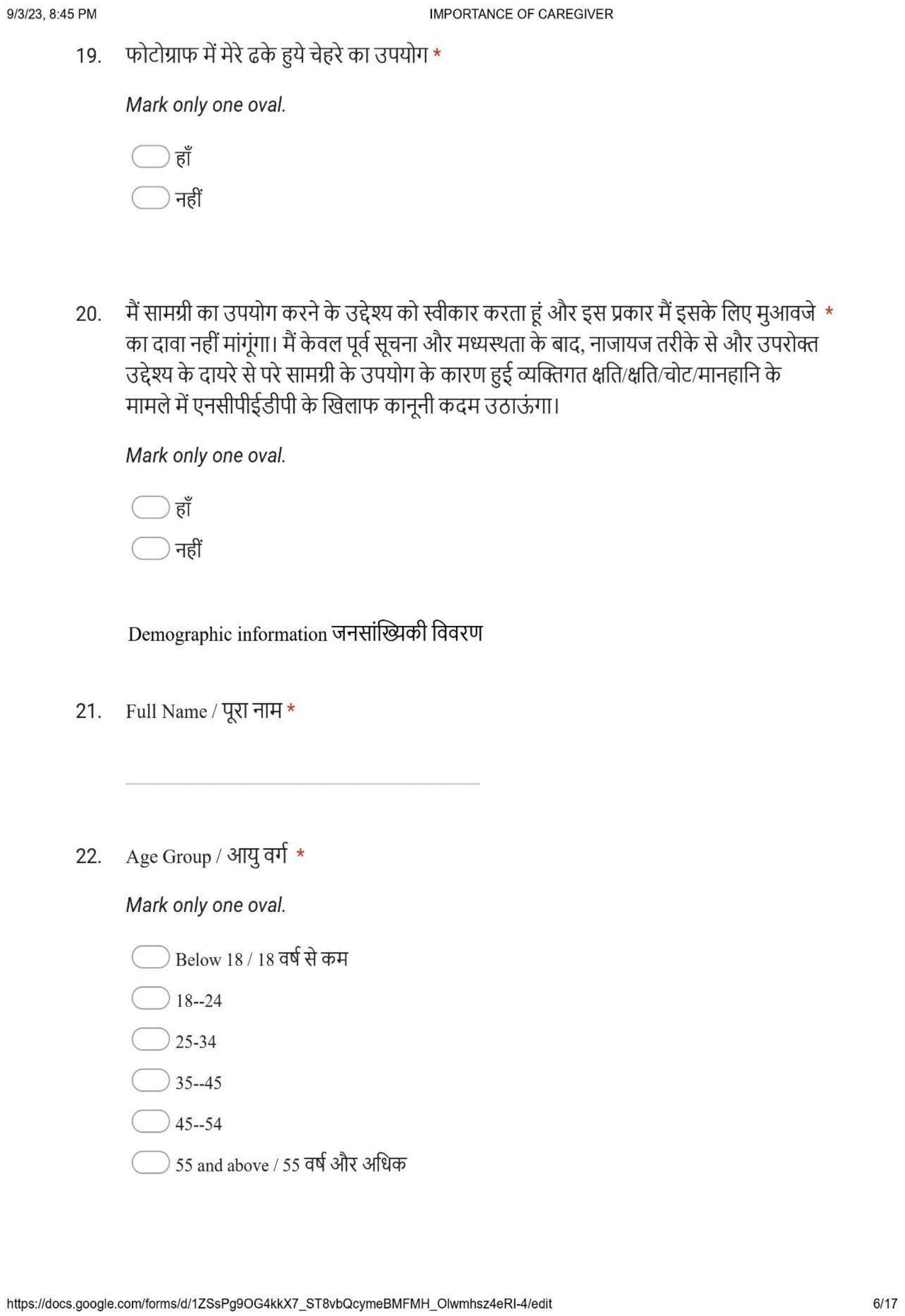

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19. फोटोग्राफ में मेरे ढके हुये चेहरे का उपयोग *

Mark only one oval.

○ हाँ
○ नहीं

20. मैं सामग्री का उपयोग करने के उद्देश्य को स्वीकार करता हूं और इस प्रकार मैं इसके लिए मुआवजे का दावा नहीं मांगूंगा। मैं केवल पूर्व सूचना और मध्यस्थता के बाद, नाजायज तरीके से और उपरोक्त उद्देश्य के दायरे से परे सामग्री के उपयोग के कारण हुई व्यक्तिगत क्षति/क्षति/चोट/मानहानि के मामले में एनसीपीईडीपी के खिलाफ कानूनी कदम उठाऊंगा। *

Mark only one oval.

○ हाँ
○ नहीं

Demographic information जनसांख्यिकी विवरण

21. Full Name / पूरा नाम *

____

22. Age Group / आयु वर्ग *

Mark only one oval.

○ Below 18 / 18 वर्ष से कम
○ 18--24
○ 25-34
○ 35--45
○ 45--54
○ 55 and above / 55 वर्ष और अधिक

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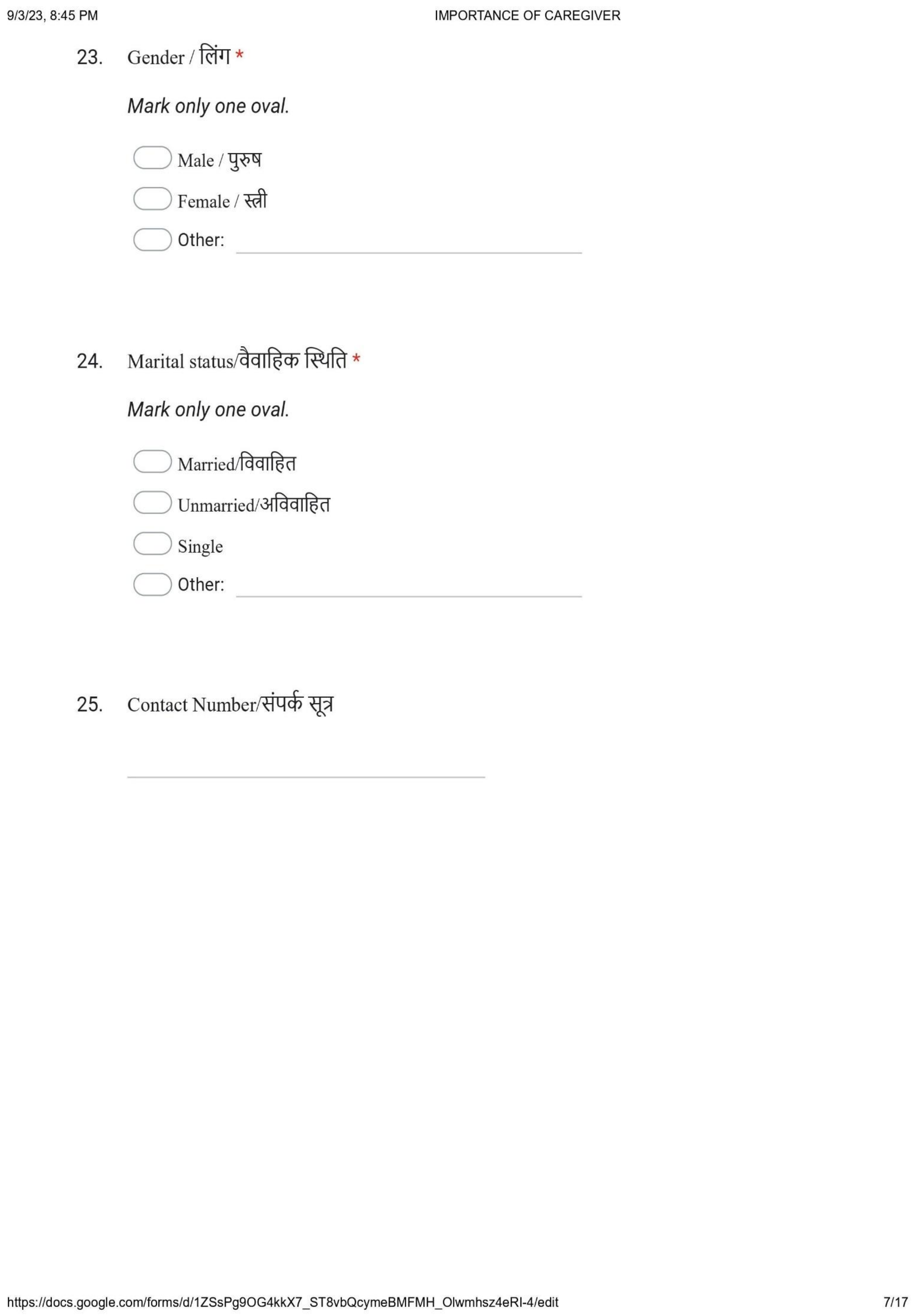

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23. Gender / लिंग *

Mark only one oval.

○ Male / पुरुष
○ Female / स्त्री
○ Other: ____________________

24. Marital status/वैवाहिक स्थिति *

Mark only one oval.

○ Married/विवाहित
○ Unmarried/अविवाहित
○ Single
○ Other: ____________________

25. Contact Number/संपर्क सूत्र

____

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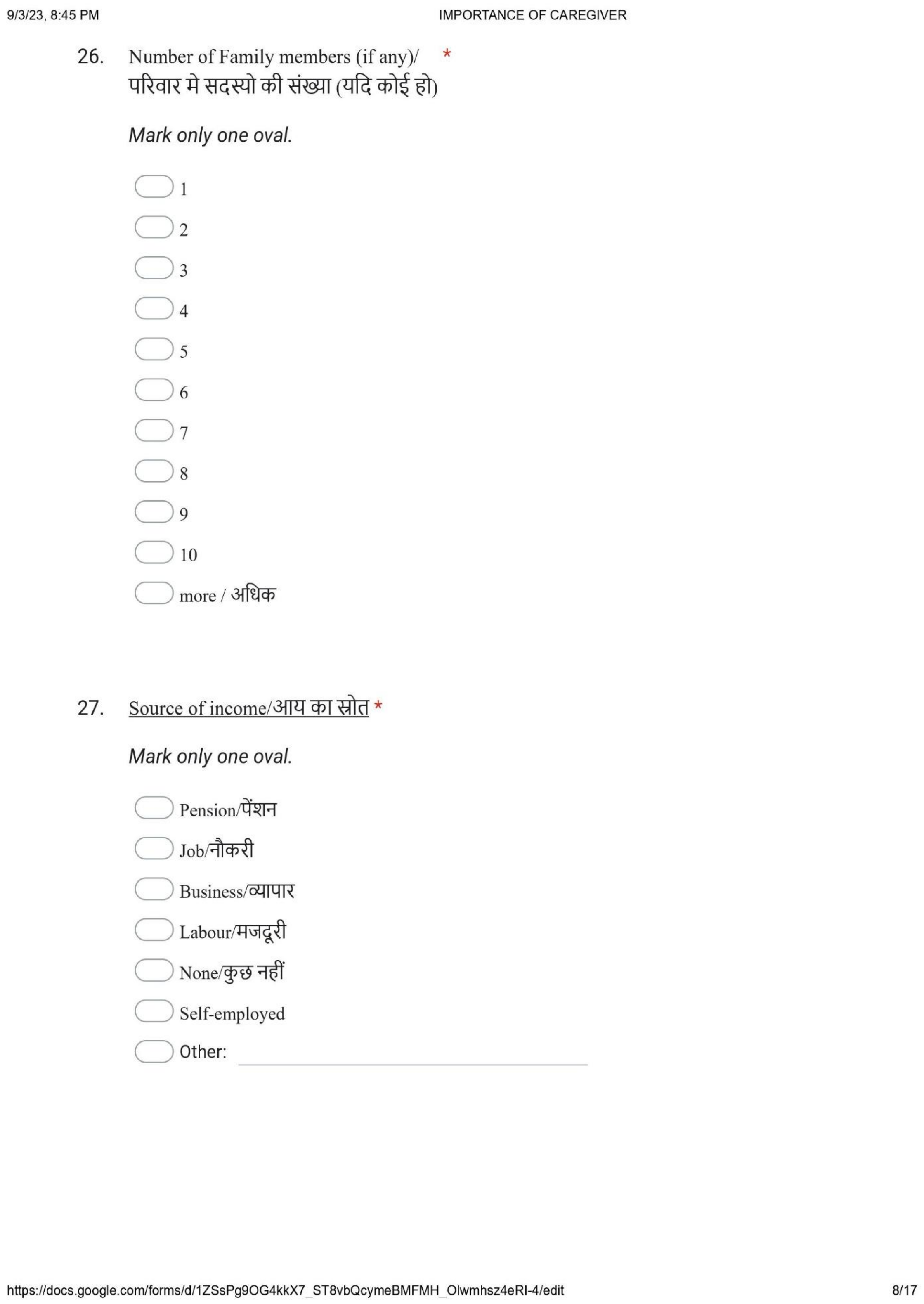

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26. Number of Family members (if any)/ परिवार मे सदस्यो की संख्या (यदि कोई हो) *

Mark only one oval.

○ 1
○ 2
○ 3
○ 4
○ 5
○ 6
○ 7
○ 8
○ 9
○ 10
○ more / अधिक

27. Source of income/आय का स्रोत *

Mark only one oval.

○ Pension/पेंशन
○ Job/नौकरी
○ Business/व्यापार
○ Labour/मजदूरी
○ None/कुछ नहीं
○ Self-employed
○ Other: ______________

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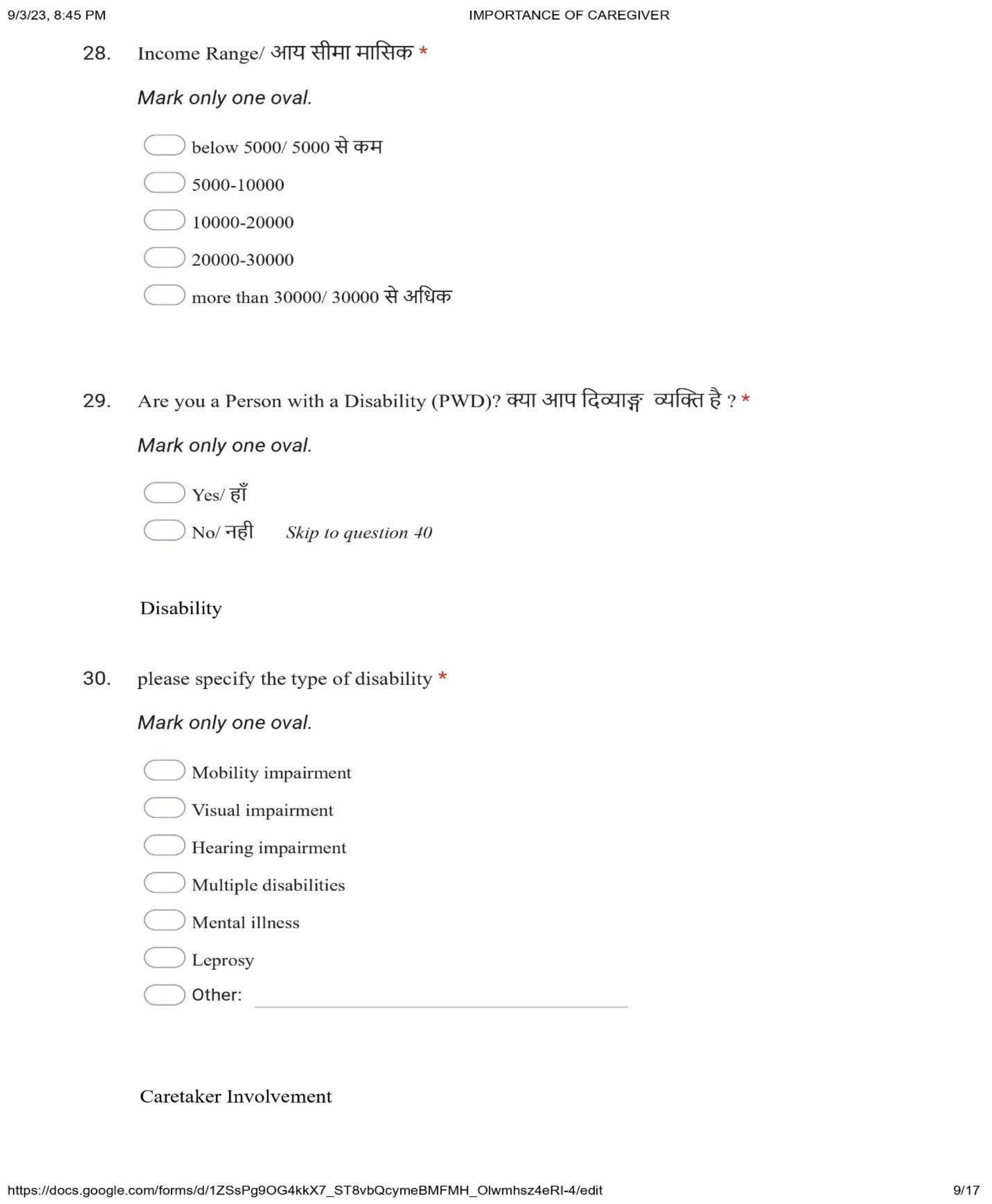

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28. Income Range/ आय सीमा मासिक *

Mark only one oval.

○ below 5000/ 5000 से कम
○ 5000-10000
○ 10000-20000
○ 20000-30000
○ more than 30000/ 30000 से अधिक

29. Are you a Person with a Disability (PWD)? क्या आप दिव्याङ्ग व्यक्ति है ? *

Mark only one oval.

○ Yes/ हाँ
○ No/ नही *Skip to question 40*

Disability

30. please specify the type of disability *

Mark only one oval.

○ Mobility impairment
○ Visual impairment
○ Hearing impairment
○ Multiple disabilities
○ Mental illness
○ Leprosy
○ Other: ______________________

Caretaker Involvement

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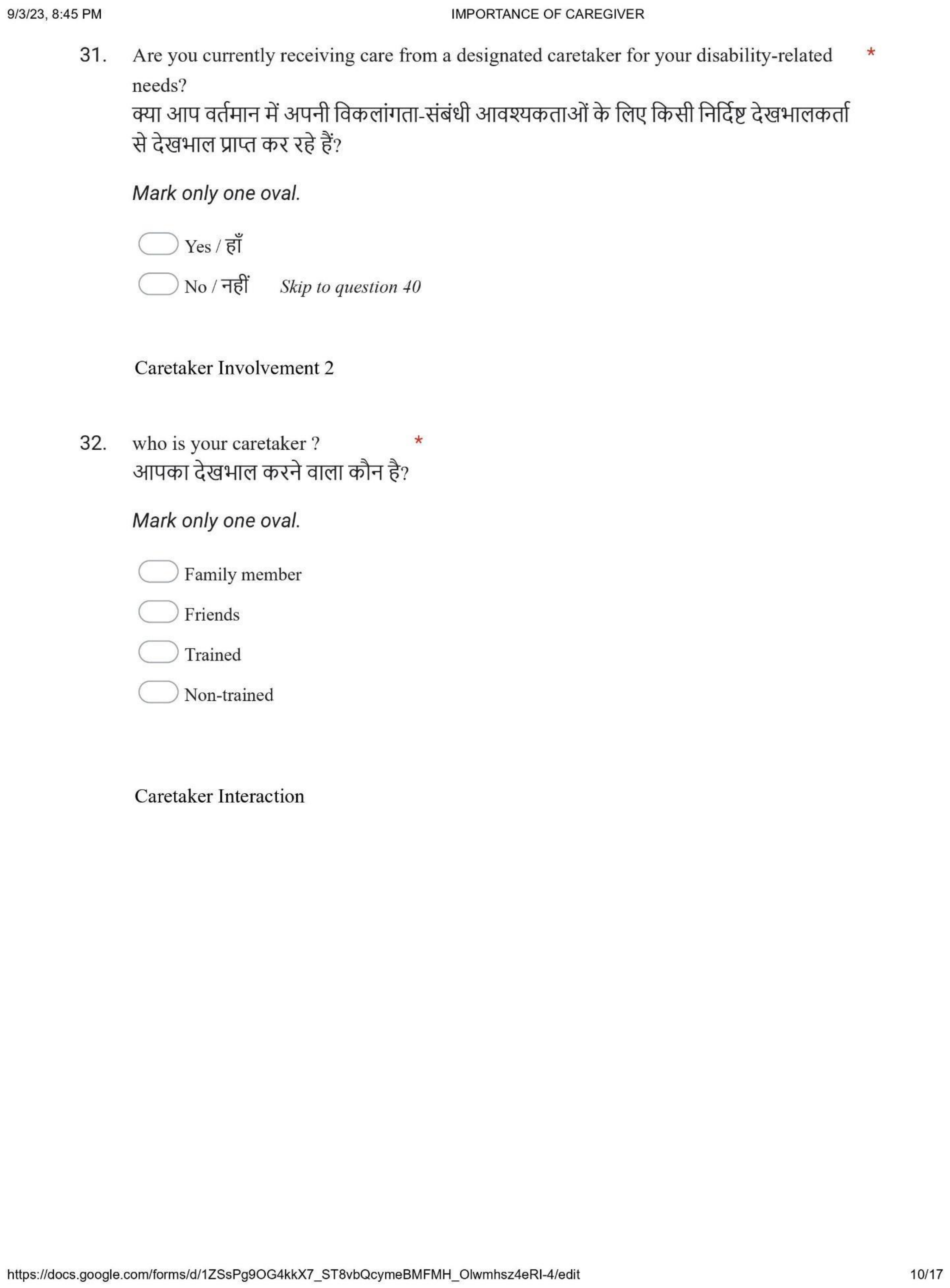

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31. Are you currently receiving care from a designated caretaker for your disability-related needs? *
क्या आप वर्तमान में अपनी विकलांगता-संबंधी आवश्यकताओं के लिए किसी निर्दिष्ट देखभालकर्ता से देखभाल प्राप्त कर रहे हैं?

Mark only one oval.

○ Yes / हाँ
○ No / नहीं *Skip to question 40*

Caretaker Involvement 2

32. who is your caretaker ? *
आपका देखभाल करने वाला कौन है?

Mark only one oval.

○ Family member
○ Friends
○ Trained
○ Non-trained

Caretaker Interaction

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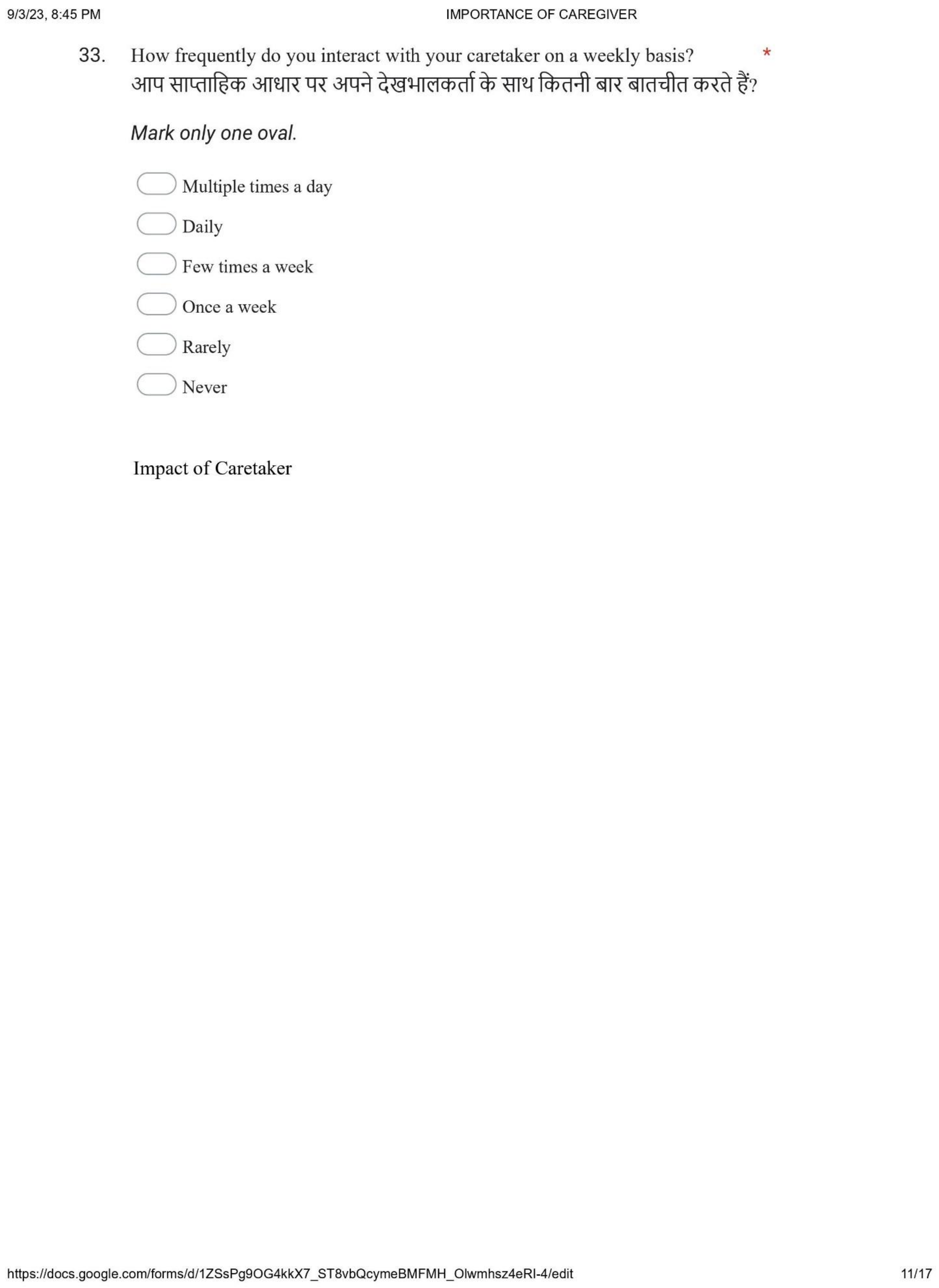

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33. How frequently do you interact with your caretaker on a weekly basis? *
आप साप्ताहिक आधार पर अपने देखभालकर्ता के साथ कितनी बार बातचीत करते हैं?

Mark only one oval.

○ Multiple times a day
○ Daily
○ Few times a week
○ Once a week
○ Rarely
○ Never

Impact of Caretaker

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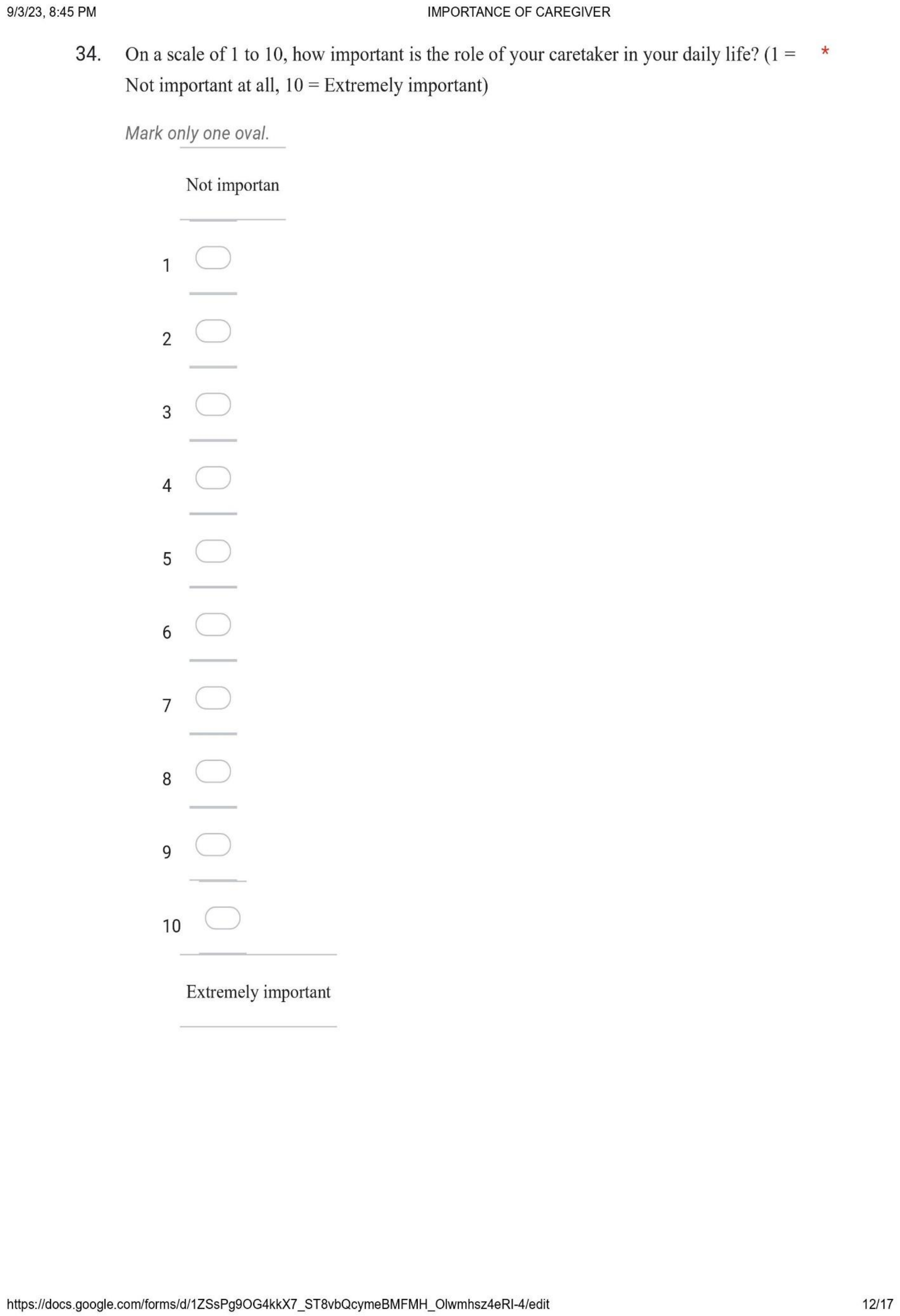

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34. On a scale of 1 to 10, how important is the role of your caretaker in your daily life? (1 = Not important at all, 10 = Extremely important) *

Mark only one oval.

Not importan

1 ○
2 ○
3 ○
4 ○
5 ○
6 ○
7 ○
8 ○
9 ○
10 ○

Extremely important

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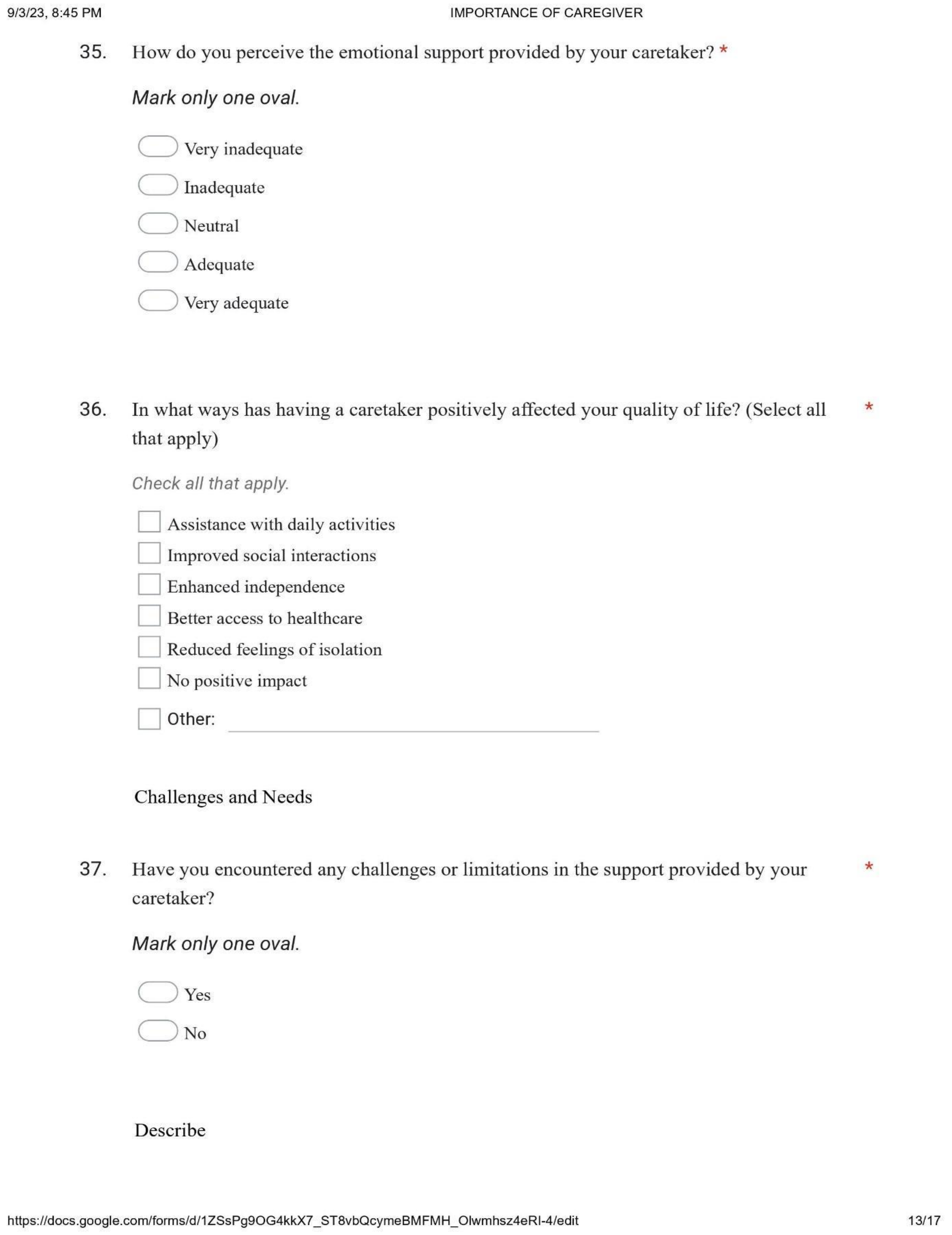

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35. How do you perceive the emotional support provided by your caretaker? *

Mark only one oval.

○ Very inadequate
○ Inadequate
○ Neutral
○ Adequate
○ Very adequate

36. In what ways has having a caretaker positively affected your quality of life? (Select all that apply) *

Check all that apply.

☐ Assistance with daily activities
☐ Improved social interactions
☐ Enhanced independence
☐ Better access to healthcare
☐ Reduced feelings of isolation
☐ No positive impact
☐ Other: ______________________

Challenges and Needs

37. Have you encountered any challenges or limitations in the support provided by your caretaker? *

Mark only one oval.

○ Yes
○ No

Describe

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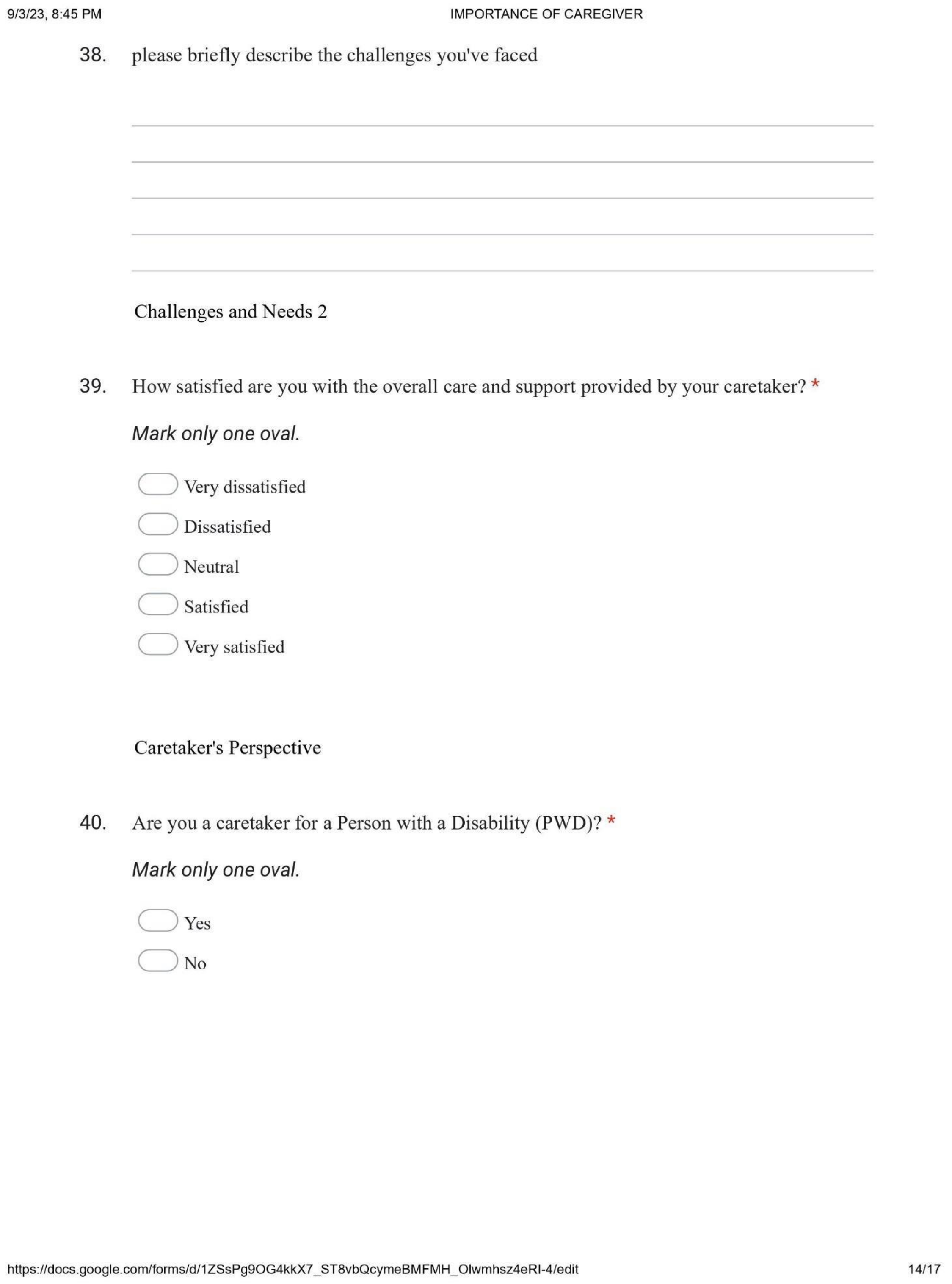

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38. please briefly describe the challenges you've faced

Challenges and Needs 2

39. How satisfied are you with the overall care and support provided by your caretaker? *

Mark only one oval.

○ Very dissatisfied
○ Dissatisfied
○ Neutral
○ Satisfied
○ Very satisfied

Caretaker's Perspective

40. Are you a caretaker for a Person with a Disability (PWD)? *

Mark only one oval.

○ Yes
○ No

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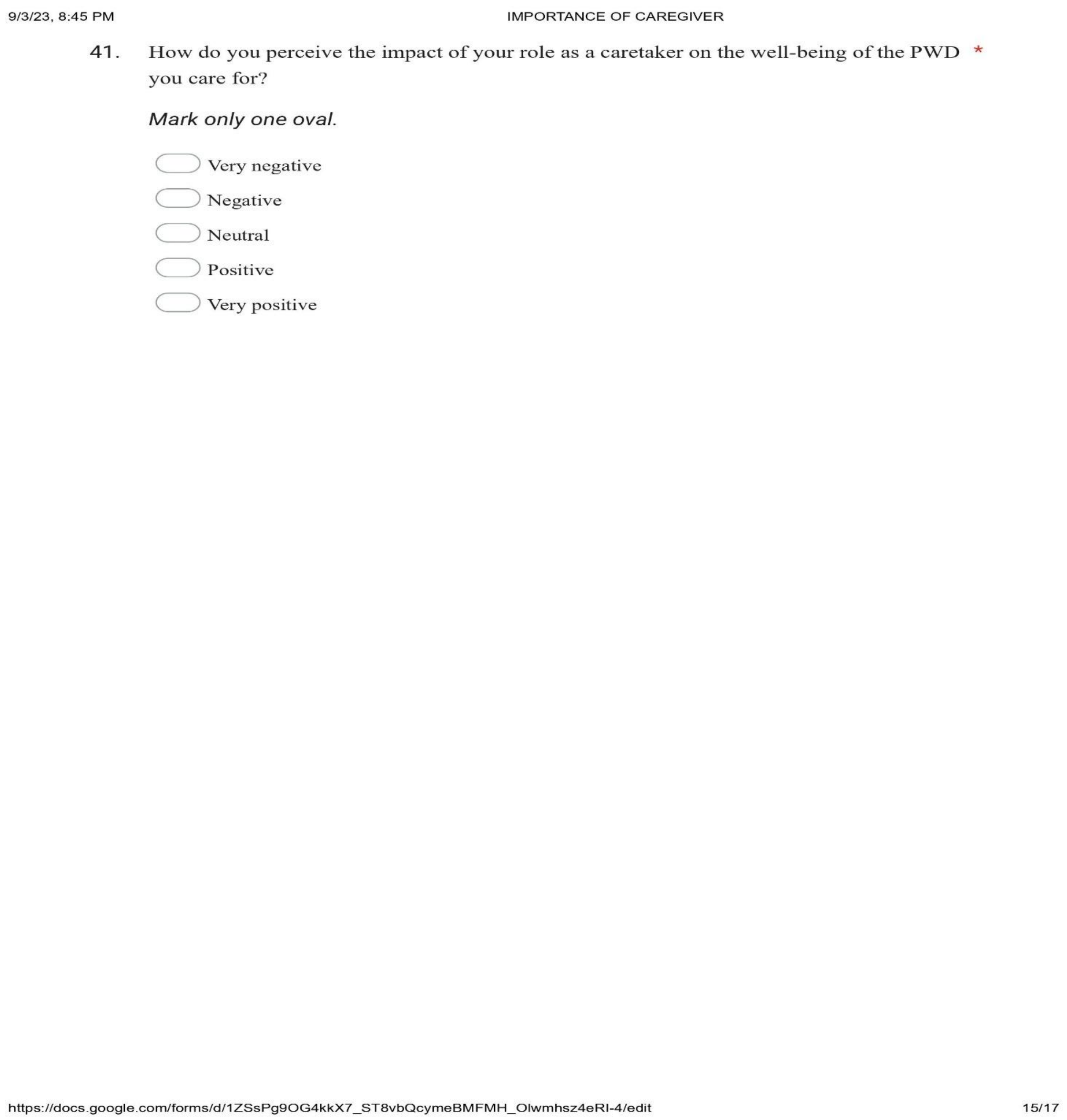

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41. How do you perceive the impact of your role as a caretaker on the well-being of the PWD you care for? *

Mark only one oval.

- ○ Very negative
- ○ Negative
- ○ Neutral
- ○ Positive
- ○ Very positive

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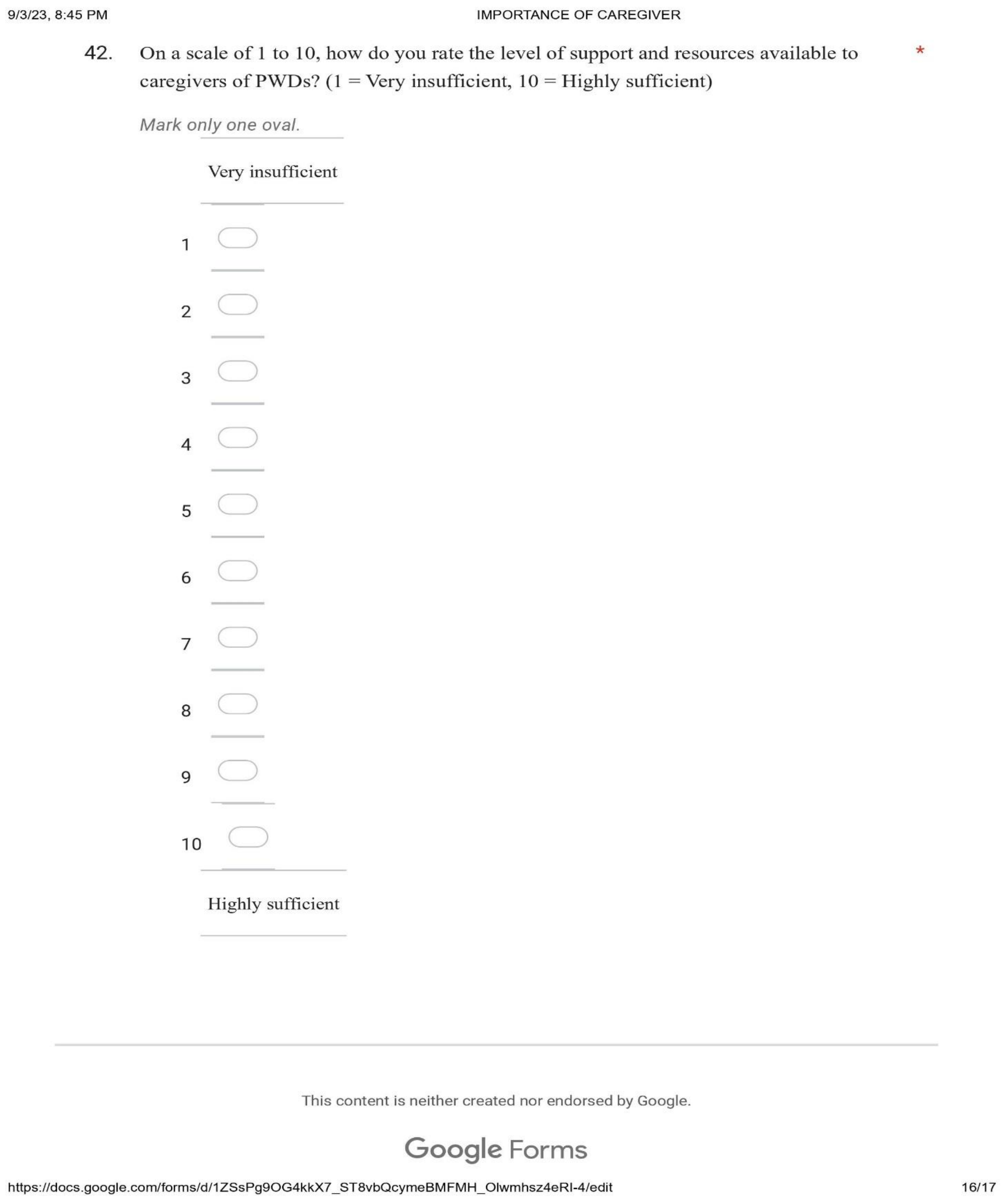

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42. On a scale of 1 to 10, how do you rate the level of support and resources available to caregivers of PWDs? (1 = Very insufficient, 10 = Highly sufficient) *

Mark only one oval.

Very insufficient

1 ○

2 ○

3 ○

4 ○

5 ○

6 ○

7 ○

8 ○

9 ○

10 ○

Highly sufficient

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