PILOT STUDY ON UNPAID CARE WORK IN RELATION TO PERSONS WITH DISABILITIES AND ASSOCIATED SOCIAL PROTECTION POLICIES

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பெண்கள் மற்றும் ஊடகக் கூட்டமைப்பு
Women and Media Collective
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PILOT STUDY ON UNPAID CARE WORK IN RELATION TO PERSONS WITH DISABILITIES AND ASSOCIATED SOCIAL PROTECTION POLICIES

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LIST OF ABBREVIATIONS AND ACRONYMS

COVID-19	Coronavirus disease 2019
CSO	Civil Society Organization
DOJF	Disability Organizations Joint Front
EAP	Economically Active Population
EIP	Economically Inactive Population
GCE O/L	General Certificate of Education Ordinary Level
LKR	Sri Lanka Rupee
SDG	Sustainable Development Goals
SSA	Social Scientists' Association
UCW	Unpaid Care Work
WMC	Women and Media Collective

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1. INTRODUCTION

Unpaid Care Work (UCW) is an invisible but essential element of a well-functioning society, which has traditionally been performed by women. This includes, among other work, caring for family members with disabilities. Despite their critical contribution to the economy, women who exclusively perform UCW are not counted among the labour force in many countries including Sri Lanka. However, policymakers, economic analysts, and most donor/international organisations persistently argue that women's labour force participation is low in Sri Lanka. For instance, labour force statistics for 2021 disclosed that out of the Economically Active Population (EAP) of 8.5 million persons in Sri Lanka, women only account for approximately 2.9 million (34.3%). In comparison, approximately 6.3 million (73.3%) of an Economically Inactive Population (EIP) of 8.5 million were women.[1] Most women who are part of the labour force often have the double burden of paid work responsibilities and their UCW responsibilities, the latter of which goes unrecognized. Historically, UCW has been absent from policy agendas and left out of official statistics, thereby obscuring the reality of women's participation in the labour force.[2]

In recent times, attempts have been made to recognize and increase the visibility of UCW. Target 5.4 under Goal 5 of the Sustainable Development Goals (SDG) which relates to Gender Equality seeks to include recognizing the economic value of Unpaid care and domestic work as a necessary element for inclusive growth and development.[3] Sri Lanka published its first Time Use Survey in 2020 that assessed the time spent by women and men on household activities.[4] The recent COVID-19 pandemic also highlighted the essential nature of UCW, even though women and care work have conspicuously been left out of stimulus packages and emergency measures announced during the pandemic in Asia, including Sri Lanka.[5]

Women and Media Collective carried out a comprehensive study on unpaid care work covering six districts in Sri Lanka over the period 2017-2020.[6] The study which brought out the extended hours spent mostly by women, on activities of care for the wellbeing of household members. Through a Time Use Survey (TUS) developed by WMC and the Social Scientists' Association, the study attempted to capture the simultaneous activities relating to care. The study gives a critical view of not only the types and range of activities, the management of time that primary caregivers extend as part of their daily lives, but also an assessment of the economic value of this work.[7]

The findings of the study led WMC to inquire further into the issues that are faced by primary carers of family members with disabilities through this pilot study on unpaid care work in relation to persons with disabilities.[8] The reality on the ground is that approximately 10 percent of the population in Sri Lanka (1.7 million) live with a disability. According to the Labour Force Survey 2021, 7.9 percent of the Economically Inactive Population (EIP) is inactive due to a physical illness or disability. In the absence of adequate and affordable disability care services, the care of these persons falls on families. Women are the primary care-givers for most family members with disabilities who require long-term care. Societal norms and expectations lead to the burden of UCW falling on women in

[1] 'Sri Lanka Labour Force Survey Annual Report - 2021' (Department of Census and Statistics, 2021), http://www.statistics.gov.lk/LabourForce/StaticalInformation/AnnualReports/2021.

[2] 'Unpaid Care Work of Women in Relation to the Care of Vulnerable Household Members in Sri Lanka - A Policy Review' (Women and Media Collective (WMC), October 2022), https://womenandmedia.org/wp-content/uploads/2022/11/Social-Protection-Policy-Review_English.pdf.

[3] 'Statistics on Unpaid Work', ILOSTAT, accessed 8 October 2023, https://ilostat.ilo.org/topics/unpaid-work/.

[4] Department of Census and Statistics. (2020). Sri Lanka Time Use Survey. statistics.gov.lk/PressReleases/TUS_FinalReport_2017

[5] 'Women's Unpaid and Underpaid Work in the Times of Covid-19 | Oxfam in Asia', 31 May 2020, https://asia.oxfam.org/latest/blogs/womens-unpaid-and-underpaid-work-times-covid-19.

[6] Kottegoda, Sepali and Pradeep Peiris (2023). 'Recogising Unpaid Care Work in Sri Lanka: Key Research Findings from Six Districts.' In, Working Hours: Exploring Gender Dimensions of Unpaid Care Work in Sri Lanka. Eds. Sepali Kottegoda and Pradeep Peiris. Women and Media Collective. Colombo.

[7] Gunawardena, Dileni and Ashwin Perera (2023). 'Valuing Unpaid Care Work in Six Districts in Sri Lanka'. In, Working Hours: Exploring Gender Dimensions of Unpaid Care Work in Sri Lanka. Eds. Sepali Kottegoda and Pradeep Peiris. Women and Media Collective. Colombo.

[8] 'The State of Economic, Social and Cultural Rights of Persons with Disabilities in Sri Lanka' (Disability Organizations Joint Front, April 2017), https://ices.lk/wp-content/uploads/2017/06/The-State-of-Economic-Social-and-Cultural-Rights.pdf, 5

most instances, resulting in inequalities among women in relation to their economic and political participation, and opportunities for leisure time and self-care.

At the same time, approximately 10% of the population in Sri Lanka (1.7 million) live with a disability.[5] According to the Labour Force Survey 2021, 7.9% of the Economically Inactive Population (EIP) is inactive due to a physical illness or disability.[7] In the absence of adequate and affordable disability care services, the care of these persons falls on families. Women are the primary caregivers for most family members with disabilities who require long-term care. Societal norms and expectations lead to the burden of UCW falling on women in most instances, resulting in inequalities among women in relation to their economic and political participation, and opportunities for leisure time and self-care.

1.1 Purpose and Objective

Against the above backdrop, the objective of this study is to contribute to evidence-based research on recognizing, reducing, and redistributing the burden of care work and the need for an overall social care policy which recognizes the need for increased investment in state-run entities that provide care services. The study was specifically conducted to explore the availability, access, and use of government and private care services and facilities for vulnerable household/family members to evaluate the potential benefits of state investment and private sector-supported entities to reduce women's UCW. The study was conducted as part of the project titled "Creating Change: Cross-Sectoral Interventions for Social Transformation" implemented by the Women and Media Collective (WMC) with financial support from the Royal Norwegian Embassy.

1.2 Methodology

The study aimed to capture the social protection initiatives available to persons with disabilities in Sri Lanka and the impact of such availability on UCW of women in relation to household members with disabilities. Taking a mixed methods approach, the study comprised both quantitative and qualitative elements. At the outset, a survey was carried out using a sample of twenty (20) households each (which had family members with disabilities) from four (4) districts, namely: Colombo, Batticaloa, Kurunegala, and Anuradhapura, equaling a total sample of Eighty (80) households. All households selected had one or more household members with disabilities and the person performing UCW in each household was selected as the respondent for this survey. The questionnaire administered to the respondents (see Annexure 1) consisted of 41 questions spanning several areas relevant to UCW vis-a-vis household members with disabilities. The survey data was supplemented by two (2) in-depth interviews from each of the four districts in which the survey was conducted. Accordingly, a total of eight (8) in-depth interviews were conducted in the four districts. Respondents for the in-depth interviews were selected using a convenience sampling method, through the organizations which carried out the survey for this study.

The fieldwork was carried out between September and December 2022. For the survey component of the study, WMC worked with one organization from each of the four districts, with extensive experience in conducting similar research. The organizations were, Disability Organizations Joint Front (DOJF) in Colombo and Batticaloa, Women's Resource Centre in Kurunegala, and AKASA Association of women with Disabilities from Anuradhapura. The survey data was analysed and tabulated by Suresh Amuhena of the Social Scientists' Association (SSA). The in-depth interviews were conducted by WMC.

1.3 Limitations

This study attempts to provide a macro view of the distribution of UCW in relation to persons with disabilities within a household in Sri Lanka and an understanding of the programmes available to provide care for these people, which are necessary to reduce the UCW burden on women. However, this study may be subject to response bias, the findings of which therefore should be generalized cautiously. Limited discourse of UCW has manifested in inadequate knowledge of the area of research, which may have influenced the responses provided by some survey respondents.

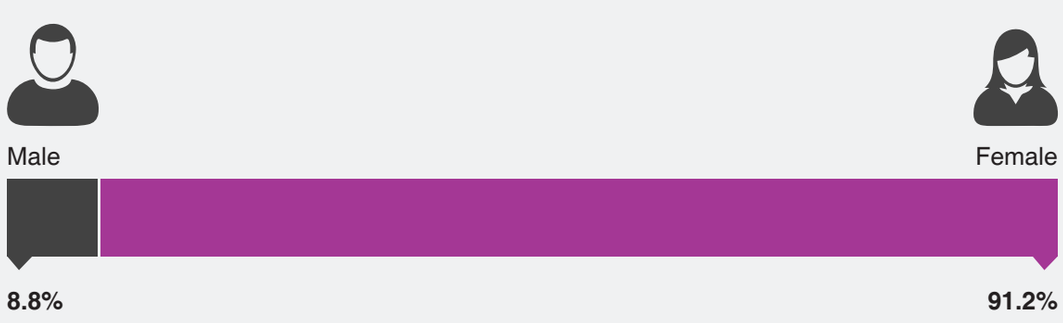
2.
PROFILE OF CARERS

Laws and policies in Sri Lanka do not address the issues of social protection and care of persons with disabilities to reduce their dependence on families for support. Therefore, their care is relegated to the private sphere, with authorities placing emphasis on the dependency of persons with disabilities. Families are called upon to provide care and assistance to persons with disabilities without formal recognition or accommodation of this role – increasing the care burden on families. This study attempted to capture the general profile of family members primarily responsible for the care of persons with disabilities within households and the general characteristics of such households.

2.1
Demographic of carers

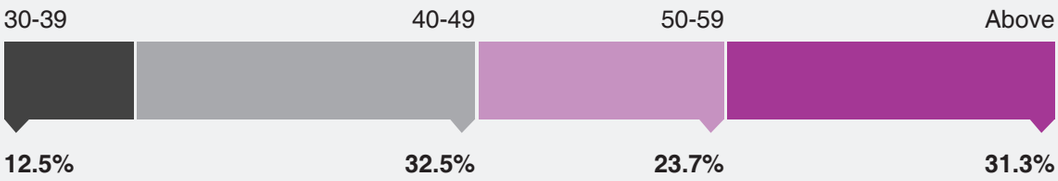
The majority of survey respondents (91.3%) were women, signifying that the majority of carers of those with disabilities are women. Approximately one-third of the respondents (32.5%) were from the 40-49 years age category while another one-third (31.3%) were above the age of 60. In contrast, the lowest percentage of carers were from the age category of 30-39 years. National Labour Force statistics indicate that women from this age category have one of the highest labour force participation rates by age group (44.2%),[7] which may account for the lower percentage of carers in this age category. In-depth interviews also indicate that women who marry and start families at a younger age are prevented from completing their education or acquiring a skill necessary for employment. As a result, these women tend to, and are expected to, take on more unpaid care responsibilities vis-à-vis Persons with disabilitiess in the family, while men, irrespective of their level of education, find employment (even as informal sector workers) outside or away from home to support the families.

Figure 1: Total survey respondents



[7] Thusitha Kumara, 'Determinants of Youth Unemployment in Sri Lanka', The Journal of Studies in Humanities 4, No. II (2018): 65–80. And 'Sri Lanka Fostering Workforce Skills through Education- Employment Diagnostic study' (ADB and ILO Regional Office for Labour and the Pacific, 2017), https://www.adb.org/sites/default/files/publication/382296/sri-lanka-employment-diagnostic.pdf.

Figure 2: Survey respondents by age categories



The ethnic breakdown of the interviewees is shown in the chart below.

Figure 3: Survey respondents by ethnicity

Reflecting the overall population in the selected districts, 66.3% of the respondents were Sinhalese, 28.8% were Tamil, and 5.0% were Muslim. The majority of respondents were residents of Pradeshiya Sabha areas (77.5%), while the lowest percentage of respondents were from Municipal Council Areas.

Table 1: Survey respondents by area of residence

Area of residence	Valid Percentage
Municipal Council area	10.0
Urban Council area	12.5
Pradeshiya Sabha area	77.5
Total number of respondents	80

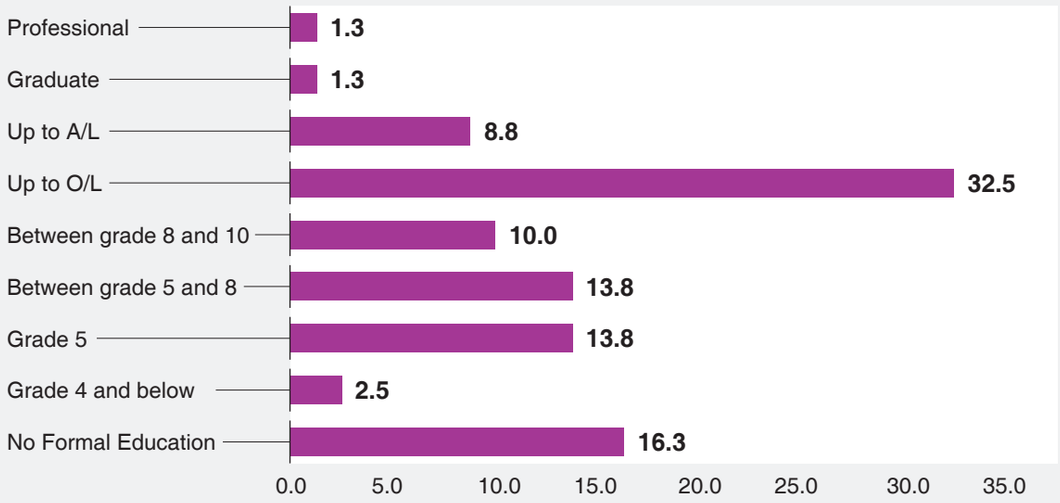
Overall, women are the primary carers in most households; however, the percentage of male respondents from Urban and Municipal Council Areas is slightly higher than that of female respondents from these areas. This could indicate that more males from urban areas take on care responsibilities when compared with males from less urban areas, which perhaps may be the result of the more cosmopolitan attitudes including toward care responsibilities of urban dwellers.

Table 2: Sex disaggregated data on survey respondents by area of residence

Area of residence	Female	Male
Municipal Council area	9.6%	14.3%
Urban Council area	12.3%	14.3%
Pradeshiya Sabha area	78.1%	71.4%
Total number of respondents	73	7

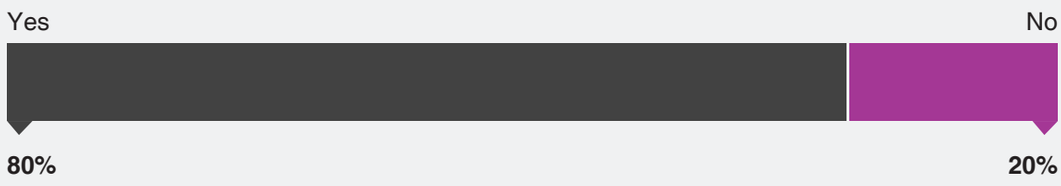
The Figure below shows that among the respondents, the highest educational qualification of 88.6% is between grades 8 and 10. One-third of the respondents (32.5%) had received education up to O/L. Only 11.4% had studied up to A/L or had higher professional qualifications. The qualitative interviews backed up national-level research findings of the correlation between the low levels of education and under- or un-employment.[8] Often, in families which take on full-time care of household members with disabilities, the members who support the household financially are employed in low-skilled and low-paying jobs due to a lack of skills necessary for better employment opportunities. This means that the care burden of household members with disabilities is borne by one or more of family members, as they cannot afford the costs involved in the care services available to persons with disabilities.

Figure 4: Survey respondents by level of education



When asked whether the respondents like to engage in employment, a significant percentage of the total sample (80%) stated that they would like to. Approximately 79.5% of women respondents surveyed responded affirmatively to this question.

Figure 5: Preference of respondents to engage in employment



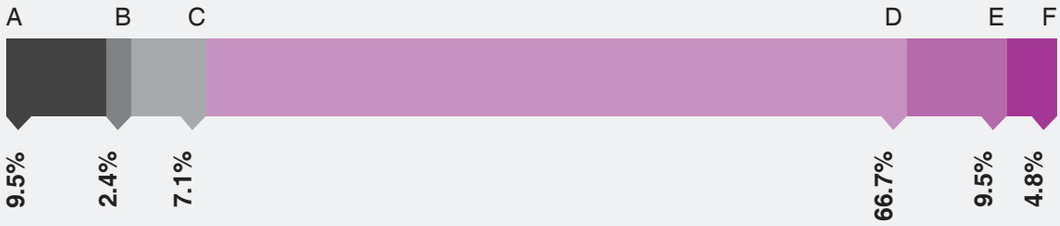
[8] Thusitha Kumara, 'Determinants of Youth Unemployment in Sri Lanka', *The Journal of Studies in Humanities* 4, No. II (2018): 65–80. And 'Sri Lanka Fostering Workforce Skills through Education- Employment Diagnostic study' (ADB and ILO Regional Office for Labour and the Pacific, 2017), https://www.adb.org/sites/default/files/publication/382296/sri-lanka-employment-diagnostic.pdf.

Table 3: Sex disaggregated data on the preference of respondents to engage in employment

Response	Female	Male
Yes	79.5%	85.7%
No	20.5%	14.3%
Total number of respondents	73	7

More than two-thirds (65.6%) of those who replied in the affirmative to the question whether they like to engage in employment, are not currently employed. The majority of the respondents who are not employed (66.7%) state that they are unable to engage in employment due to the fact of having to care for the household member with disabilities, who is often a child. This illustrates that caregiving responsibilities have an adverse impact on the ability to take on paid employment.

Figure 6: Reasons for not being currently employed



A – Could not find a job
B – I am physically incapable of engaging in formal employment
C – There is no one to look after children
D – There is no one to look after child with disabilities
E – There is no one to do the housework
F – My housband/wife does not like

When considering the gender dimensions of the responses to this question, the survey found that more than two-thirds (67.5%) of female respondents who indicated that they like to engage in employment but are not currently employed, were unable to secure employment due to responsibilities associated with care work. This indicates that a significant proportion of women are left out of the workforce and by extension, the ability to earn an income, due to caregiving responsibilities. In-depth interviews indicate that the hesitancy in parents of children with disabilities, stem from the perception that the child will not be taken care of properly by any other person but themselves. Often mothers would not take up employment even when opportunities for employment are available. Concerns regarding the safety and security of children, especially girl children, also contribute to women preferring not to take up employment outside the home. Even when there are other opportunities for employment, they prefer self-employment such as sewing clothes and handicrafts. Qualitative research also disclosed that often, men in rural areas who support the households financially are employed either overseas or in urban areas away from home and only visit their families occasionally. This situation also contributes to women having to bear most of the care responsibilities with no time for employment.

Table 4: Sex disaggregated data on the reasons for not being currently employed

Reasons for not being employed	Female	Male
Could not find a job	7.5%	50.0%
I am physically incapable of engaging in formal employment	2.5%	0.0%
There is no one to look after the children	7.5%	0.0%
There is no one to look after the child with disabilities	67.5%	50.0%
There is no one to do the housework	10.0%	0.0%
My husband/ wife does not like	5.0%	0.0%
Total number of respondents	40	2

As the table below shows, of those respondents who are employed (34.4%), the majority (54.5%) were engaged in self-employment, while 40.9% was employed in the private sector. None was employed in the government sector.

Table 5: Sectors of employment of respondents (both sexes) currently employed

Sector	Valid Percentage
Private sector employment	40.9
Self-employment	54.5
Farming or home gardening	4.5
Total number of respondents	22

According to Table 6 below, a higher percentage of women respondents were self-employed (55.6%) while none of the male respondents was engaged in farming or home gardening. Half of those employed in the private sector were men (50.0%), while the female private sector employment rate was only 38.9%.

Table 6: Sex disaggregated data on the sectors of employment of respondents currently employed

Sector	Female	Male
Private sector employment	38.9%	50.0%
Self-employment	55.6%	50.0%
Farming or home gardening	5.6%	0.0%
Total number of respondents	18	4

As can be seen in Table 7, the main reason for approximately one-third of the respondents (37.5%) stating that they do not like to engage in employment is their perceived lack of necessary qualifications for employment.

Table 7: Main reasons of respondents (both sexes) who do not like to engage in employment for such preference

Reason	Valid Percentage
I do not like to do a job	12.5
I do not think it is appropriate	12.5
I feel I am not qualified enough	37.5
Other	37.5
Total number of respondents	16

As indicated in the following table, all these respondents were women. However, approximately a quarter of the female respondents (26.6%) stated either that they prefer not to have a job or that they think it is not appropriate for them to have employment, as the reasons for their lack of employment. These sentiments were also found in the in-depth interviews when caregiving women voiced concerns about their own ability to be successful due to the lack of necessary skills; they preferred to take care of the household or there was spousal opposition to women being employed. Furthermore, financial constraints prevent women from up-skilling themselves as vocational training costs money, which they are not able to afford. Therefore, women welcome opportunities for vocational training necessary for home-based self-employment provided by government entities, CSOs, and other charitable organizations. However, as these programmes are often conducted with limited resources, only selected persons receive such training and start-up resources necessary to establish their own business.

"My husband doesn't like me going out for a job. I take care of the disabled older child. The younger child goes to school and is in Grade 10. He (my husband) wants me to stay at home with the two kids as he fears for their safety if left on their own."

– Female respondent 1 from Anuradhapura

Table 8: Sex disaggregated data of the main reasons of respondents who do not like to engage in employment for such preference

Reason	Female	Male
I do not like to do a job	13.3%	0.0%
I do not think it is appropriate	13.3%	0.0%
I feel I am not qualified enough	40.0%	0.0%
Other	33.3%	100.0%
Total number of respondents	15	1

2.2
Household characteristics

A. Household members:

In relation to household characteristics, Table 9 below illustrates that households with four members accounted for the highest percentage of households surveyed (28.8%). Approximately 90.0% of the households had five members or fewer, out of which 42.6% had only two or three members.

Table 9: Composition of households

Number of household members	Valid Percentage
1	3.8
2	21.3
3	21.3
4	28.8
5	15.0
6	7.5
7	1.3
8	1.3
Total number of respondents	80

In more than one-third of the households surveyed (38.8%), the survey respondent, who is also the caregiver of the family member with disabilities, is a contributor to household income.

Table 10: Contributors to household income

Contributors to household income	Percentage of Cases
Respondent her/himself	38.8%
Spouse	42.5%
Son or Daughter	30.0%
Parent/s	6.3%
Other	5.0%
Total number of respondents	98

Only 21.3% of the households depended on more than one source of income such as private and government sector employment, pensions, government social welfare, and income from self-employment.

Table 11: Number of sources of income

No. of sources of income	Valid Percentage
More than one source of income	21.3
Only one source of income	78.8
Total number of respondents	80

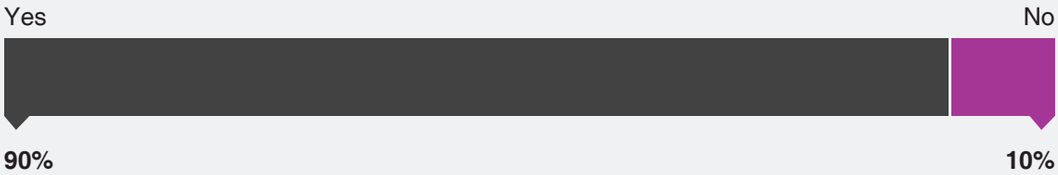
Of these households, the majority were of Sinhalese ethnicity (88.2%), while none of the Muslim households had more than one source of income. In-depth interviews shed light on the numerous expenses related to persons with disabilities including mobility devices, sensory aids, medication, and different types of therapy. Even when some of these expenses are borne by third parties such as donors and charity organizations or provided by state hospitals, the cost of transport involved in accessing these services and organizations is significant. Given that most households fall below the poverty line (see Table 15 below), offsetting even transport costs with a single source of income strains the households and deprives them of an adequate standard of living.

Table 12: Ethnicities of households which relied on more than one source of income

Ethnicity of households which relied on more than one source of income	Valid Percentage
Sinhalese	88.2%
Tamil	11.8%
Muslim	0.0%
Total number of respondents	17

Of the surveyed households, 90.0% had at least one member who was not an income earner. The non-income-earning member relied on the respondent or another income-earning household member for expenses related to food, clothing, education, transport, healthcare etc.

Figure 7: Non-income earning members of the household



In 65.3% of the surveyed households, the non-income earner was the child of the respondent. The non-income earner was the sibling or the spouse in 12.5% and 13.9% of households respectively.

Table 13: Profile of non-income earning members of the households

Relationship	Percent of Cases
Child	65.3%
Sibling	12.5%
Parent/s	8.3%
Parent-in-law	8.3%
Grandparent/s (self or spouse)	1.4%
Husband/Wife	13.9%
Total number of respondents	79

B. Income and expenditure of the household

a. Income

The main source of income in 36.3% of the households was through employment in the private sector. In 31.3% of surveyed households, the main source of income was self-employment, while in 18.8% of the households, the main source of income was from informal labour. Only 5.0% of households relied on household members' income from government sector employment or from government social welfare as the main source of income.

Table 14: Main sources of income of the household

Sector	Valid Percentage
Government employment	5.0
Private sector employment	36.3
Self-employment	31.3
Farming or home gardening	1.3
Pension	2.5
Govt. social welfare	5.0
Labourer	18.8
Total number of respondents	80

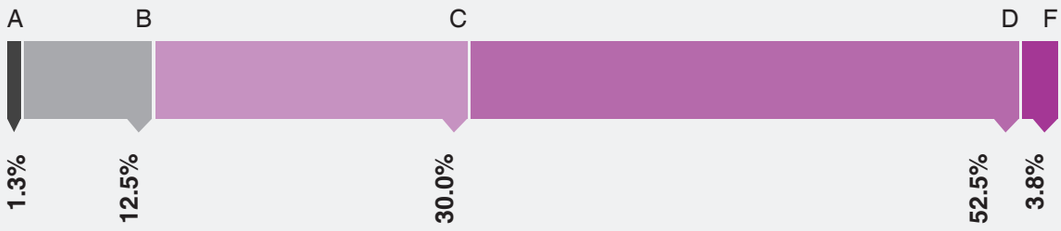
In addition to the main source of income, in-depth interviews revealed that extended family members, neighbours, community members, and civil society organizations (CSOs) may make contributions to the families of persons with disabilities to offset some of the expenses involved in caring for a person with a disability. In some cases, even hospital staff pool funds to purchase necessary medication and other equipment for persons with disabilities when families are unable to bear the costs.

"Once a lab asked for Rs. 20,000 for a blood test which had to be sent to India. I told the lab that I don't have that much money. Then the nurses collected the money and gave it for the sample to be sent to India."

– Female respondent 2 from Colombo

More than half of the surveyed households[9] (52.5%) received a monthly income between LKR 20,001-50,00. This income must be read in light of the last recorded national poverty line (December 2022), which was LKR 13,777.[10] Only 3.8% of the households received a monthly income of LKR 50,001-100,000.

Figure 8: Average monthly income of households



A – Less than 5,000 LKR
B – Less than 10,000 LKR
C – 10,001 – 20,000 LKR
D – 20,001 – 50,000 LKR
E – 50,001 – 100,000 LKR

Qualitative information highlighted the hardships some households face in trying to save enough of their monthly income to spend on expenses related to the family member with a disibility. For instance, respondents disclosed that income earners who live away from home, virtually live on one meal a day to save as much as possible of the monthly salary to send home for the expenses of the household. Even with such measures, the majority of four-member (28.6%) and five-member (21.4%) households only received between LKR 20,001-50,000 of monthly income. Therefore, it could be assumed that the majority of the surveyed households fell below the poverty line.

"I earn about 20,000 per month. My husband works in Colombo. He earns about 30,000 per month and if he skips meals he can send home about 20,000. Expenses are now high because of extra-help classes necessary for the younger daughter."

– Female respondent 1 from Anuradhapura

[9] A household is defined as: "…a one-person household or a multi-person household. A one-person household is a unit where a person lives by himself and makes separate provision for his food, either cooking himself or purchasing. A multi-person household is a group of two or more persons who lives together and has a common arrangement for cooking and partaking food. Boarders and servants who share the meals and housing facilities with other members of the household are also considered as members of the household," Source: 'Household Income and Expenditure Survey – Final Report 2019' (Department of Census and Statistics, 2019), http://www.statistics.gov.lk/IncomeAndExpenditure/StaticalInformation/HouseholdIncomeandExpenditureSurvey2019FinalReport.

[10] 'Official Poverty Line by District: December 2022', Department of Census and Statistics, accessed 9 October 2023, http://www.statistics.gov.lk/povertyLine/2022_new.

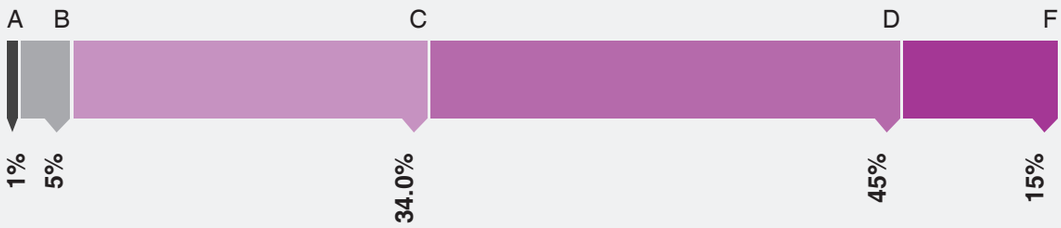
Table 15: Household income disaggregated by the number of household members

Number of household members	Less than 5,000 LKR	Less than 10,000 LKR	10,001 – 20,000 LKR	20,001 – 50,000 LKR	50,001 – 100,000 LKR
1	0.0%	0.0%	4.2%	4.8%	0.0%
2	0.0%	40.0%	20.8%	19.0%	0.0%
3	100.0%	50.0%	12.5%	16.7%	33.3%
4	0.0%	10.0%	37.5%	28.6%	33.3%
5	0.0%	0.0%	12.5%	21.4%	0.0%
6	0.0%	0.0%	8.3%	7.1%	33.3%
7	0.0%	0.0%	0.0%	2.4%	0.0%
8	0.0%	0.0%	4.2%	0.0%	0.0%
Total number of respondents	1	10	24	42	3

b. Expenditure

The average monthly expenditure of the highest percentage of surveyed households (45.0%) was between LKR 20,001- 50,000. Another 34.0% of the surveyed households incurred monthly expenses within the range of LKR 10,001- 20,000.

Figure 9: Average monthly expenditure of households



A – Less than 5,000 LKR
B – Less than 10,000 LKR
C – 10,001 – 20,000 LKR
D – 20,001 – 50,000 LKR
E – 50,001 – 100,000 LKR

When asked to name the main items for which monthly expenditure was incurred, the majority of respondents prioritized food (98.8%), medical expenses (77.5%), and electricity and fuel (66.3%). Other priority items were education for children (32.5%), transport (28.8%), water (27.5%), and hygiene items (28.8%). In-depth interviews showed that households with limited incomes have to prioritize expenses each month, often resulting in defaulting some payments. For instance, utility bills accumulate over a few months because they have to prioritise and ensure educational expenses and medical expenses are covered. Women carers were particularly concerned to ensure that their non-disabled children receive uninterrupted access to education, especially in relation to girl children. Therefore, they would allocate a certain amount of the monthly income to cover costs related to transport, extra classes, and stationery for those children.

Table 16: Items of expenditure of households

Items	Percentage of Cases
Food	98.8%
Clothing	23.8%
Medical	77.5%
Education for children	32.5%
Electricity & fuel	66.3%
Transport	28.8%
Communication	11.3%
Tuition for children	11.3%
Entertainment	1.3%
House maintenance	3.8%
Water	27.5%
Social expenses	7.5%
Hygiene items / sanitary products	28.8%
Loan repayment / lease/ house rent	15.0%
Cooking fuel	16.3%
Total number of respondents	360

In terms of expenditure specifically incurred in caring for the household member with disabilities, the majority of households spent on food (73.8%), medicine (71.3%), transport (46.3%), and sanitary facilities (27.5%). Qualitative interviews highlighted the adverse impact of the exponential increases in essential items including medicine and other care products for persons with disabilities. Families have even reduced the use of diapers for persons with disabilities who are incontinent as the cost is prohibitive, burdening the caregivers with more work in cleaning the disabled family member regularly. Excessive prices of medicine and other necessities for persons with disabilities sometimes also result in other family members having to forego their own medical needs to be able to afford essential medical items for the persons with disabilities. This has led to those other family members suffering from long-term non-communicable diseases, taking a severe toll on their physical and mental health. Only some households have incurred expenses in relation to physiotherapy (15.0%) and psychosocial therapy (12.5%). In-depth interviews revealed that families usually rely on government hospitals and not-for-profit organizations providing such services at no additional cost except transport as these services could be expensive to procure privately. Significantly, only 5.0% of households mentioned incurring expenditure to hire domestic helpers in the specific context of caring for the household member with disabilities.

Table 17: Items of expenditure specific to household members with disabilities

Item	Percentage of Cases
Food	73.8%
Medicine	71.3%
Physiotherapy	15.0%
Psychosocial therapy	12.5%
Paid help	5.0%
Education	15.0%
Transport facilities	46.3%
Sanitary facilities	27.5%
Total number of responses	213

C. Employment of domestic help

When asked if the respondents employed domestic help, only 18.8% of the respondents mentioned that they employed domestic help. Domestic help included paid domestic workers who come for a few hours daily or weekly as well as live-in domestic helpers. The majority of households did not employ domestic helpers.

Figure 10: Employment of domestic help

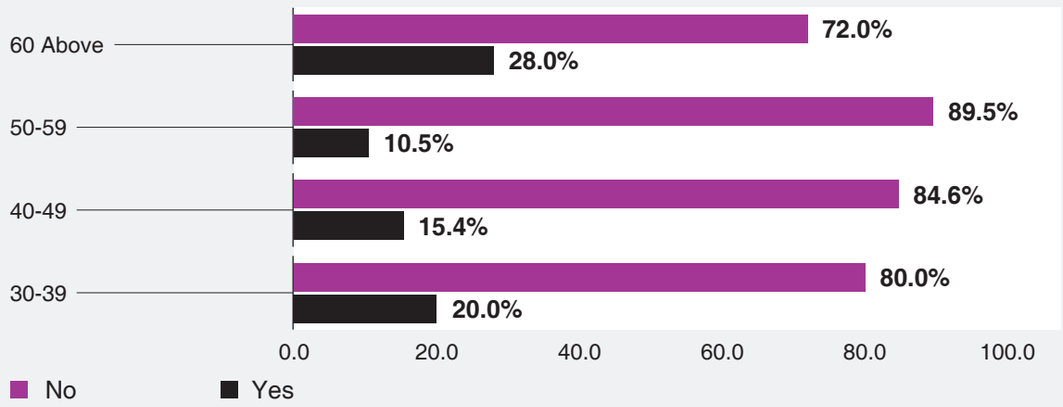
As shown in the following table, all of the respondents who employ domestic help belonged to the Sinhala ethnicity, while none of the Tamil and Muslim respondents reported employment of domestic helpers (See Tables 36 and 37 below, which show that the non-dependent household members in the majority of these households do not contribute to general household chores or to the care of dependents).

Table 18: Ethnicities of households employing domestic help

Response	Sinhalese	Tamil	Muslim
Yes	28.3%	0.0%	0.0%
No	71.7%	100.0%	100.0%
Total number of respondents	53	23	4

Of the 18.8% who employ domestic help, the majority belong to the “above 60” age category. More often, younger respondents seem to manage without domestic help as illustrated in the figure below.

Figure 11: Households employing domestic help disaggregated by age groups of respondents



Household income may also play a significant part in the decision to employ domestic help. As in-depth interviews revealed, households that have persons with disabilities often rely on household members other than the primary caregiver, and/or the extended family, and neighbours for the care of the persons with disabilities as they cannot afford to pay for domestic help.

3.
FACTORS OF DISABILITY

The types of disability affecting family members of the respondents varied. According to responses of the interviewees, more than half of those with disabilities suffered from physical disabilities (51.3%), 20% had sensory impairments, 18.8% had developmental disability and 10% had behavioural or emotional disabilities (See figure 12).

Figure 12 Types of disability affecting family members of the respondents

A – Physical
B – Developmental
C – Behavioural or emotional
D – Sensory impaired

When delving into the reasons for such disability, interviews with respondents revealed that 56.3% of those with disabilities have had the disability since birth, whereas 12.6% of them have developed the disability a few months to years from birth. Approximately one-fifth of the sample had been disabled as a result of an accident.

Table 19: Reasons for disability

Reasons for disability	Valid Percentage
From birth	56.3
As a result of an accident	18.8
Few years from birth	8.8
Few months from birth	3.8
Armed conflict	3.8
Disease	5.0
Medical negligence	3.8
Total number of respondents	80

The majority of the household members with disabilities were adults above 20 years of age (68%). It was found that 18.8% of the family members with disabilities were children within the age category of 5-15 years. This age group includes children who are subject to the compulsory education directive of the Government, i.e., 6-14 years. Only 1.3% were children below 5 years of age. In-depth interviews disclosed that even though some state schools have special units for children with disabilities, these lack the capacity, infrastructure, and trained teachers to meet the requirements of the entire spectrum of disabilities that were reported in the households in the survey. Therefore, these schools assess the children prior to intake to determine if the unit has the capacity to accommodate the child. Parents of children who are not admitted must seek educational opportunities in the private sector or offered by charitable or other not-for-profit organizations for these children.

Figure 13 Age disaggregated data of household members with disabilities

A – Below 5 years
B – 5 to 15 years
C – 16 to 20 years
D – Above 20 years

A significant proportion of female persons with disabilities (65.8%) and of male persons with disabilities (85.7%) of the surveyed households were above the age of 20. Another 20.5% of female persons with disabilities were between the ages of 5-15 years.

Table 20: Sex disaggregated data of household members with disabilities according to age groups

Age categories	Female	Male
Below 5 years	1.4%	0.0%
5 to 15 years	20.5%	0.0%
16 to 20 years	12.3%	14.3%
above 20 years	65.8%	85.7%
Total number of respondents	73	7

Of the persons with disabilities in the households surveyed, more than half (57.5%) require assistance with all of their work, while only 12.5% do not require any assistance. Qualitative interviews disclosed that providing special care to the family member with disabilities, especially for those who are wholly dependent on the carer, increases the care burden of the caregiver. This in turn prevents the caregiver from engaging in any paid employment, recreational activities, or other social engagements, essentially isolating the carer from the wider society.

Table 21: Types of assistance (special care) household members with disabilities require

Special care required	Percentage of Cases
They do their work alone	12.5%
Bathing	6.3%
Administering medication	5.0%
Assistance in all work	57.5%
Feeding	6.3%
Assistance in using the toilet	5.0%
Taking to clinics/ hospital	10.0%
Taking to school	6.3%
Washing their clothes	2.5%
Supervising them to ensure they do not come to any physical harm	5.0%
Education	1.3%
Total number of respondents	94

4.
ACCESS TO CARE SERVICES

Women's low labour force participation rate in Sri Lanka is considered a drawback to the development of the country. Due to time poverty, most caregiving women are unable to take up paid work. In this context, the availability of affordable and accessible care services for persons with disabilities is important to facilitate their carers, who are mostly women, to join the labour force. Hence, the survey focused on the perceptions of the availability of, awareness of, and accessibility to both government and private care centres and preschools for persons with disabilities.

4.1
Availability of government care centres for those with disabilities

As indicated in the table below, the vast majority of respondents (96.5%) claim that government care centres for those with disabilities are either not available in their areas or they are not aware of the availability of such services in the vicinity.

Table 22: Awareness of the availability of government care centres for those with disabilities

Response	Valid Percentage
Yes	6.3
No	57.5
Not aware	36.3
Total number of respondents	80

In relation to the levels of awareness of the availability of these services, 35.6% of women were not aware of such services. A significant percentage of women (58.9%) stated that such services are not available as opposed to 42.9% of men who responded "No", when asked if government care centres for those with disabilities are available in their area.

Table 23: Sex disaggregated data of the awareness of the availability of government care centres for those with disabilities

Response	Female	Male
Yes	5.5%	14.3%
No	58.9%	42.9%
Not aware	35.6%	42.9%
Total number of respondents	73	7

A primary factor was the lack of information on available services, a lack of focus on target beneficiaries etc. Service users often get to know about the existence of services through word of mouth. There appears to be no formal or streamlined dissemination of information to potential users of these government care services.

Out of the minority who stated "Yes", only 20% have availed of their services. While the base is statistically insignificant to quantify, 50% of those who have not availed of government care services had done so because they stay home to take care of a disabled family member (See also Section 2.1 above), while another 25% have not availed of these services due to the cost involved.

Table 24: Reasons for not availing of government care centres

Reasons for not availing of government care centres	Percentage of Cases
I stay at home and take care of this person/ persons	50.0%
We cannot afford it	25.0%
non-acceptance of child	25.0%
Total number of respondents	4

In-depth interviews further revealed that even though some types of government care services are available in their areas, those do not always offer services suitable for every type of disability (see also Section 3 above). At the same time, other reasons such as the inability to afford costs such as transport and nominal monthly fees necessary to access these services, fear of abuse of the person with a disability, lack of resources in government institutions, and the lack of information of the services offered by care centres contribute to families of persons with disabilities not availing of these services.

"She was enrolled in several places such as the School for the Deaf in Kalutara and another Home near Saliyapura. But, we had to bring her back. At the care home, she was the only deaf and dumb person. She was disruptive every time we visited her. Even if she had continued there, we would've had to bring her back now that she is paralysed."

– Daughter-in-law of respondent 2 from Anuradhpura

4.2
Availability of private care centres for those with disabilities

Similar to government care services, 92.5% claim that private care centres for those with disabilities (including not-for-profit organizations such as CSOs) are either not available in their areas or they are not aware of the availability of such services. A higher percentage of respondents were not aware of the existence of such services (45.0%) compared to those who were unaware of the availability of government care centres (36.3%). In comparison to those who stated that government care services are available in their areas (6.3%), a slightly higher percentage (7.5%) of respondents stated that private care services were available in their areas.

Table 25: Awareness of the availability of private care centres for those with disabilities

Response	Valid Percentage
Yes	7.5
No	47.5
Not aware	45.0
Total number of respondents	80

However, in-depth interviews indicate that not-for-profit organizations do in fact offer care services for persons with disabilities in these areas. CSOs identify potential beneficiaries through community outreach and in certain instances even provide transport costs for families to bring their family member with disabilities to these centres. These organizations collaborate with each other and with government care services, to make referrals to expand the services offered to persons with disabilities.

The survey found that women respondents displayed greater awareness of the availability or otherwise of these services than men. Only 43.8% of women were unaware if these private care centres were available in contrast to 57.1% men.

Table 26: Sex disaggregated data of the awareness of the availability of private care centres for those with disabilities

Response	Female	Male
Yes	6.8%	14.3%
No	49.3%	28.6%
Not aware	43.8%	57.1%
Total number of respondents	73	7

Even though statistically insignificant, approximately two-thirds (66.7%) of those who said that they are aware of the availability of private care centres, also stated that they have availed of the services of such centres. The remaining one-third who have not availed of such services stated that they did not do so because they stay home to take care of the child with disabilities. As mentioned in Section 2.1, the choice of mothers to care for their children with disabilities at home and by themselves stems from safety concerns and the belief that they can take better care of the child than an institution.

Table 27: Percentage of those who have availed of the services of private care centres

Response	Valid Percentage
Yes	66.7
No	33.3
Total number of respondents	6

4.3
Availability of preschools which accept children with disabilities

The survey found that the perceived availability of preschools which accept children with disabilities is higher in the survey areas than other disability care services. While 21.3% of the respondents stated that such preschools exist in their areas, 31.3% were unaware of the availability of such preschools.

Table 28: Awareness of the availability of preschools which accept children with disabilities

Response	Valid Percentage
Yes	21.3
No	47.5
Not aware	31.3
Total number of respondents	80

As depicted in the table below, similar to the levels of awareness in relation to the other disability-related care services available, women displayed higher levels of awareness than men on the availability of preschools which accept children with disabilities. All of those respondents who stated that preschools are available were women. Only 30.1% of women were unaware of the availability of such preschools, in contrast to 42.9% of men.

Table 29: Sex disaggregated data of the awareness of the availability of preschools which accept children with disabilities

Response	Female	Male
Yes	23.3%	0.0%
No	46.6%	57.1%
Not aware	30.1%	42.9%
Total number of respondents	73	7

In contrast to availing of the services of other care services, the majority of respondents who stated that preschools which enroll children with disabilities are available (82.4%) said that they have enrolled their children in these preschools.

Table 30: Percentage of those who have availed of the services of preschools which accept children with disabilities

Response	Valid Percentage
Yes	82.4
No	17.6
Total number of respondents	17

However, in-depth interviews revealed that some households were hesitant to enroll the child with disabilities in these schools as they were unsure if the particular type of disability would be accommodated in these schools. At the same time, in certain instances children have been turned away from preschools and schools because their disability is different from the disabilities of the majority in those institutions; the institution does not have any expertise in providing services for that particular disability; or the child is considered a disruption to the other children.

A common thread which emerged from in-depth interviews is that all care services, be it government or non-governmental, despite limited availability, in fact improve the quality of life of persons with disabilities as well as their families. Importantly, these services provide skills training for suitable persons with disabilities while also equipping even the most severely disabled with life skills necessary to fend for themselves such as toilet training and feeding themselves as well as providing therapy to check disruptive mood swings. Some services even equip caregivers with the skills necessary to provide care at home, such as nasal feeding, physiotherapy, and how to deal with extreme moods.

5. PARTICIPATION OF HOUSEHOLD MEMBERS IN CARE AND HOUSEHOLD ACTIVITIES

Time poverty due to UCW (because of the time and labour expended in caring for dependent household members) prevents women from taking up paid work and often from taking part in public and cultural life. However, the participation of other household members in care and household activities lessens the care burden placed on unpaid carers. This study attempted to capture the extent of the UCW burden of the household members responsible for the care of family members with disabilities and the extent to which non-dependent household members contribute to care and household activities.

Survey respondents were provided with a list of activities typically associated with UCW in relation to maintaining a household and caring for family members with disabilities. They were asked if they engaged in any one or more of the activities as an unpaid care worker. All respondents performed one or more of the activities listed. While all respondents performed care work for their family members with disabilities, the activities they performed vis-à-vis the household member with disabilities varied as the dependence of such household members also varied. More than two-thirds of the respondents bathed (73.8%), looked after* (77.5%), and administered medicine (67.5%) to the household member with disabilities, while more than 60% of the respondents (61.3%) also fed such household members. The majority (90-95%) of respondents were involved in household activities of cooking (90%), washing clothes (95%), cleaning the house (95%), and grocery shopping (88.8%) in addition to caring for the household member with disabilities.

Table 31: List of activities respondents perform in the household

Activity	Yes	No
Feeding children and/or person/child/ren with disabilities	61.3	38.8
Bathing children and/or person/child/ren with disabilities	73.8	26.3
Looking after* children and/or person/child/ren with disabilities	77.5	22.5
Feeding elders	0	100.0
Bathing elders	2.5	97.5
Looking after elders	6.3	93.8
Giving medicine to person/child/ren with disabilities	67.5	32.5
Providing recreation for person/child/ren with disabilities	32.5	67.5
Cooking for the household	90.0	10.0
Washing and drying clothes	95.0	5.0
Cleaning the house	95.0	5.0
Feeding pets	38.8	61.3
Cleaning and maintaining the garden	63.8	36.3
Grocery shopping	88.8	11.3

*'Looking after' was meant to refer to activities other than feeding and bathing dependents. This activity could include dressing dependents, helping them to the bathroom, making sure they are safe and comfortable etc.

The following table reveals that more than two-thirds of the sample performed at least one household chore alongside their care work.

Table 32: Percentage of respondents who perform at least one household chore in addition to their care work

Activity	Percentage of respondents who also performed cooking, cleaning, and washing clothes
Feeding children and/or person/child/ren with disabilities	65.2
Bathing children and/or person/child/ren with disabilities	78.8
Looking after children and/or person/child/ren with disabilities	83.3
Looking after elders	4.5
Giving medicine to person/child/ren with disabilities	71.2
Providing recreation for person/child/ren with disabilities	36.4

The survey also revealed that the respondents were the primary persons responsible for the majority of the activities listed above. Without exception, they were all (100.0%) responsible for caring for their household members with disabilities. At the same time, more than 90.0% of them were also primarily responsible for other household chores such as cooking (94.4%), cleaning (92.1%) and washing clothes (93.4%). It is also noteworthy that approximately 90% of the respondents appear to consider themselves responsible for chores such as feeding pets and providing recreation for the family member with disabilities, even though only around one-third of the respondents (38.8% and 32.5% respectively) in fact performed such tasks.

Table 33: Primary person responsible for the activities within the household

Activity	Person primarily responsible for the activity					
	Respondent her/himself	Spouse	Son or daughter	Parent	Caregiver of the disabled person	Other household member (Daughter-in-law)
Feeding children and/or person/child/ren with disabilities	100.0	0.00	0.00	0.00	0.00	0.00
Bathing children and/or person/child/ren with disabilities	100.0	0.00	0.00	0.00	0.00	0.00
Looking after one child and/or person/child/ren with disabilities	100.0	0.00	0.00	0.00	0.00	0.00
Feeding elders	0.00	0.00	0.00	0.00	0.00	0.00
Bathing elders	100.0	0.00	0.00	0.00	0.00	0.00
Looking after elders	100.0	0.00	0.00	0.00	0.00	0.00
Providing recreation for person/child/ren with disabilities	100.0	0.00	0.00	0.00	0.00	0.00
Giving medicine to person/child/ren with disabilities	100.0	0.00	0.00	0.00	0.00	0.00
Cooking for the household	94.4	4.2	0.00	0.00	1.4	0.00
Washing and drying clothes	93.4	5.3	0.00	0.00	1.3	0.00
Cleaning the house	92.1	2.6	2.6	1.3	0.00	1.3
Feeding pets	90.3	0.00	3.2	3.2	3.2	0.00
Cleaning and maintaining the garden	92.2	3.9	2.0	2.0	0.00	0.00
Grocery shopping	81.7	11.3	2.8	2.8	1.4	0.00

As the following table illustrates, of those identified as primarily responsible for the activities, an overwhelming majority were women, accounting for more than 90% for each activity except feeding the pets and grocery shopping. A comparatively higher percentage of men were responsible for grocery shopping than for any other activity (22.5%).

Table 34: Sex disaggregated data of the primary person responsible for the activities within the household

Activity	Female	Male
Feeding children and/or person/child/ren with disabilities	91.8	8.2
Bathing children and/or person/child/ren with disabilities	93.2	6.8
Looking after children and/or person/child/ren with disabilities	91.9	8.1
Feeding elders	0.00	0.00
Bathing elders	100.0	0.00
Looking after elders	100.0	0.00
Giving medicine to person/child/ren with disabilities	94.4	5.6
Providing recreation for person/child/ren with disabilities	96.2	3.8
Cooking for the household	98.6	1.4
Washing and drying clothes	97.4	2.6
Cleaning the house	96.1	3.9
Feeding pets	87.1	12.9
Cleaning and maintaining the garden	98.0	2.0
Grocery shopping	77.5	22.5

As time poverty is a serious barrier for women engaged in UCW to take part in paid work or cultural life, the study sought to inquire into the time respondents spent on care and household activities. On average, respondents spent more than 10 hours (624.6 minutes) each day on looking after children and/or the persons with disabilities in the household. In addition, approximately 2.5 hours were spent on cooking for the household and more than 3 hours on washing clothes and cleaning the house. These figures illustrate that the respondents engage in UCW far longer than is legally allowed for paid employment. The Shop and Office Employees (Regulation of Employment and Remuneration) Act of 1954 regulating the work hours of employees of shops and offices only permits 8-hour work days[11] while the Factories Ordinance of 1942 only permits 9 hours of work per day for women and young persons.[12] It could therefore be inferred that respondents contributing to household income spend a significant amount of time on both paid employment and UCW, which severely restricts time available for self-care. This adversely affects their physical and emotional well-being.

[11] Section 3 of the Act

[12] Section 67 of the Ordinance

Table 35: Average time spent on care and household activities

Activity	Average minutes
Feeding children and/or person/child/ren with disabilities	105.8
Bathing children and/or person/child/ren with disabilities	73.6
Looking after children and/or person/child/ren with disabilities	624.6
Bathing elders	60.0
Looking after elders	396.0
Giving medicine to person/child/ren with disabilities	51.6
Providing recreation for person/child/ren with disabilities	96.2
Cooking for the household	150.9
Washing and drying clothes	114.4
Cleaning the house	71.4
Feeding pets	55.4
Cleaning and maintaining the garden	58.7
Grocery shopping	69.9

In-depth interviews confirmed that women engaged in UCW have no time for recreational activities. They begin their day before sunrise (as early as 4 or 5 a.m.) and continue working until nightfall. Often, caregivers can concentrate on other chores only after the persons with disabilities goes to sleep. Sometimes, women have spent decades caring for the persons with disabilities without taking a break in the form of going away from home to visit relatives or for holidays. In addition to being deprived of recreation, being the primary or at times the sole caregiver for a persons with disabilities without taking time off takes a toll on the health of the caregiver. Interviews repeatedly highlighted that caregivers tend to prioritize the Persons with disabilities they care for over their own health, sometimes ignoring potentially life-threatening conditions. In other instances, household members provide care at home due to the non-availability of other options. They consider it a mandatory, less-than-palatable obligation with no respite.

> "The doctor asked me to get myself admitted to the hospital because I have a fracture in my elbow. But I can't do that because no one in the house knows to feed him and I'm afraid that the child will get weak. So the doctor told me to write a letter that I am leaving on my own consent. If I go back they will not admit me again."
>
> – Respondent 1 from Colombo

Against the above background, less than half of the respondents (41.3%) stated that non-dependent household members, who are not routinely responsible for any household chores or care work, contribute to household chores in general. In contrast, 52.5% responded that non-dependent household members contribute to the care of dependents including the care of household members with disabilities.

Figure 14: Contribution of non-dependent household members to household chores

Figure 15: Contribution of non-dependent household members to the care of dependents including household members with disabilities

One significant factor which contributes to the lack of assistance from other household members either for household chores or care duties is that these members are either senior citizens unable to contribute or are school-going children. Caregiver-mothers tend not to use the services of the children for any chore due to the concern that it may disrupt their education. However, it was observed that non-disabled children assist the parents with caregiving duties, often when the primary caregiver is away. In relation to household members with severe disabilities requiring specialized care, only the primary caregiver is often equipped to care for the Persons with disabilities, having received instructions and training from hospitals or other care centres. Hence these caregivers prefer to perform the task themselves without delegating the care to other household members. In some instances, other household members are reluctant to undertake care responsibilities due to the nature of the disability.

> "When I am at home he (the grandson) doesn't help much. But, when I'm not at home or ill, he assists with cleaning the house, preparing the bed for his mother, preparing tea etc."
>
> – Female respondent 1 from Batticaloa

Non-dependent household members contributing to general household chores were highest amongst the respondents belonging to the Muslim ethnicity (50.0%), while it was lowest amongst the Tamil households (26.1%).

Table 36: Ethnicity-based disaggregated data of the contribution of non-dependent household members to household chores

Response	Sinhalese	Tamil	Muslim
Yes	47.2%	26.1%	50.0%
No	52.8%	73.9%	50.0%
Total number of respondents	53	23	4

However, higher percentages of non-dependent household members from the Sinhala and Tamil ethnicities contributed to the care of dependents within the household. Accordingly, while 60.0% of respondents belonging to the Sinhalese ethnicity stated that non-dependent household members contribute to the care of dependent household members, 34.8% of respondents of Tamil ethnicity responded in the affirmative.

Table 37: Ethnicity based disaggregated data of the contribution of non-dependent household members to the care of dependents including household members with disabilities

Response	Sinhalese	Tamil	Muslim
Yes	60.4%	34.8%	50.0%
No	39.6%	65.2%	50.0%
Total number of respondents	53	23	4

Even though statistically insignificant to quantify, interestingly, more male respondents benefitted from the assistance of non-dependent household members for both general household chores (71.4%) as well as for care work within the household (71.4%). In contrast, only 38.4% of the female respondents stated that non-dependent household members contributed to household chores, while a slightly higher percentage (50.7%) stated that non-dependent household members contributed to the care of dependent household members.

Figure 16: Sex disaggregated data relating to receiving assistance from other household members for household chore

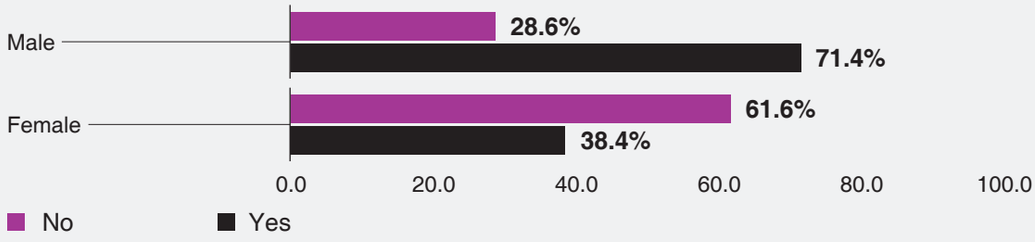
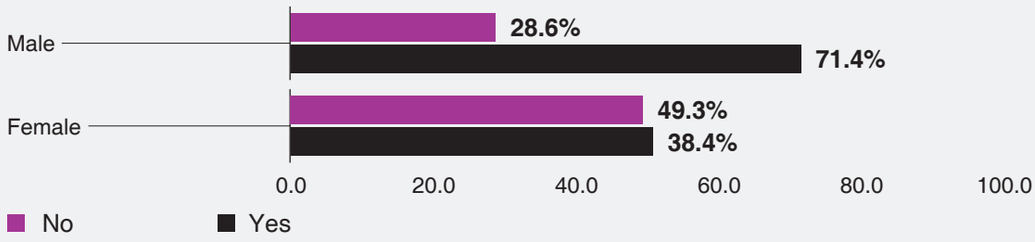


Figure 17: Sex disaggregated data relating to receiving assistance from other household members for the care of dependent household members



6.
ACCESS TO SOCIAL BENEFIT SCHEMES

Social benefit and protection schemes geared towards poverty alleviation afford families of Persons with disabilities income security and reduce their vulnerability to risks associated with poverty. These also allow Persons with disabilities to enjoy their rights and improve their access to care. However, social protection and welfare expenditure allocations are limited as these programmes and budgets must compete with other development priorities for funding, which hinders adequate service provision to persons with disabilities. The survey posed a set of questions to the respondents to determine if any of the households surveyed received social security.

A majority of survey respondents (83.8%) stated that their households benefit from government welfare schemes.

Table 38: Percentage of those who have availed of the services of preschools which accept children with disabilities

Response	Valid Percentage
Yes	83.8
No	16.3
Total number of respondents	80

Of the respondents who receive government welfare, respondents belonging to the age category 30-39 years receive welfare benefits the least. At the same time, respondents belonging to the age category 40-49 years receive welfare benefits the most.

Table 39: Percentage of households benefitting from government social security schemes disaggregated by age groups of respondents

Response	30-39	40-49	50-59	Above 60
Yes	70.0%	92.3%	78.9%	84.0%
No	30.0%	7.7%	21.1%	16.0%
Total number of respondents	10	26	19	25

The majority of the surveyed households (72.1%) receive the disability allowance provided by the government, while 57.4% of the households receive Samurdhi benefits. Findings show that some families benefit from more than one social security scheme.

Table 40: Types of government welfare received

Social security scheme	Percentage of Cases
Samurdhi	57.4%
Disability allowance	72.1%
Permanent monthly allowance	8.8%
Allowance through the Ministry of Social Services, Central Government	4.4%
Senior citizens Allowance	13.2%
Widow's Allowance	2.9%
Total number of responses	108

However, in-depth interviews disclosed that the Disability Allowance and Senior Citizens Allowance had not been disbursed in two months. Even though, the Disability Allowance had previously been credited to bank accounts of beneficiaries or guardians, the process has become more cumbersome in recent times. Now, guardians of beneficiaries are required to collect the allowance from the Samurdhi Bank in person, which inconvenience these households and caregivers further. Guardians and caregivers opt to take the family member with disabilities to expedite the process, which otherwise takes several hours. The officials usually expedite payments when they see person with disability. This process also involves additional costs in travelling to collect the payment, which increases if the person with disability is also transported. More importantly, the interviews revealed the inadequacy of these allowances, especially in comparison to the expenses involved in the care of persons with disabilities and rising inflation.

> "Previously, it was directly deposited in to my account. But now I have to hire a three-wheeler and take this child with me to collect it. It costs Rs. 600. If I go alone they question as to how I receive the allowance when I'm not disabled. So, I have to take this child with me. When my sister-in-law, who is a person with a disability, went to collect her allowance, she left at 11 a.m. and came back around 1 p.m. But if I go with this child I can get it within 30 minutes."
>
> – Female respondent from Colombo

Furthermore, only one respondent claimed to receive support from the private sector or non-government entities. Approximately half of the households (45.0%) receive less than LKR 5,000 as benefits, while 41.3% receive between LKR 5,001-15,000 (See Section 4.3 above for further information on other services offered by private sector or non-governmental entities).

"She gets Rs. 5000 per month. But, it isn't enough to cover the costs of her medicine. This one medicine which used to cost only Rs. 150 is now Rs. 450. Anyway, we haven't even received that Rs. 5000 in two months now."

– Female respondent 2 from Anuradhapura

Table 41: Amounts received through social benefit schemes

Amount received	Valid Percentage
Less than 5,000 LKR	45.0
5,001 – 15,000 LKR	41.3
None	13.8
Total number of respondents	80

Access to information is an important component of social security systems, as it provides the opportunity for participation and prevents corruption and inefficiency. The survey findings disclose that the respondents mostly (71.3%) receive information of these schemes from local- level government officials. More than a quarter (27.5%) of the respondents received information from family and neighbours. Some respondents received information from multiple sources.

Table 42: Sources of information on welfare schemes

Source	Percentage of Cases
From media	6.3%
From Government officers	71.3%
From Government officers	5.0%
From family or neighbours	27.5%
Total number of responses	88

7. CONCLUSION

The care of persons with disabilities is relegated to the private sphere in Sri Lanka. With authorities placing emphasis on the dependency of persons with disabilities, families are called upon to provide care and assistance to persons with disabilities without any formal recognition or accommodation of their role. This has increased the care burden on families. This report attempted to capture the impact of UCW on women's labour force participation using household-level data from Colombo, Batticaloa, Kurunegala, and Anuradhapura districts. The study reveals that the majority of carers of household members with disabilities are women, thus disproportionately burdening women with UCW within the household. Women in the age group of 30-39 years record the lowest percentage of carers, perhaps because this age group has one of the highest national labour force participation figures. Despite being interested in paid employment, many are prevented from taking on paid employment due to their UCW responsibilities, which are often in relation to a child. Not many respondents employed domestic help, perhaps due to affordability factors, which only increased the UCW burden. Significantly, the household income of a majority of survey respondents fell below the poverty line, making only essential expenditure possible within households.

As the majority of family members with disabilities require assistance with all of their work but paid caregivers and domestic help are unfeasible in light of the constraints of household income, the burden of the unpaid caregiver has increased significantly. Survey findings revealed that both Government and private care services are either not available or the majority of potential users are not aware of the availability of such services. Out of the minority of those who stated that they are aware of such services, most did not avail of such services because they stay at home to take care of the persons with disabilities, thereby depriving the labour force as well as themselves of the opportunity to generate income. Some of the respondents did not use these services due to the costs involved. Preschools that accept children with disabilities tend to be the most widely available form of care service. As such, a majority of respondents have enrolled their children in these preschools, which may have a positive impact on the UCW burden of such respondents and their labour force participation.

Time poverty acts as one of the main barriers in the labour force participation of women engaged in UCW. The majority of the respondents engaged in a variety of household chores in addition to caring for persons with disabilities. The respondents were also primarily responsible for the performance of the majority of chores, even though other household members contribute to household chores and care work to a certain extent. As a result, on average, a considerable amount of time was spent on taking care of the persons with disabilities (10 hours), cooking (2.5 hours) and washing clothes and cleaning the house (3 hours) which is more than the legally permissible 8-hour limit for paid employment. More male respondents were seen to be receiving assistance from non-dependent household members for both the performance of household chores and UCW. This may point to entrenched gender stereotypes and expectations of division of labour within society which view UCW as the prerogative of women who therefore do not require assistance, whereas men engaged in UCW are essentially performing non-traditional and alien activities as a result of which, they require assistance.

Almost all respondents were not recipients of any welfare scheme while 83.8% benefited from government social security schemes. 72.1% received the government disability allowance while some families received assistance from more than one social security scheme. Nevertheless, almost half of the households receive less than LKR 5000 as benefits, the insignificant sum of which does not allow unpaid care workers to employ necessary help or to avail themselves of what few care services are available. Recipients of these schemes also have

various barriers to accessing funds including delays in payments and having to incur transport costs to collect payments. Adequate social security benefits are necessary for women from impoverished backgrounds performing UCW to lessen their care burden and to contribute to the economy and their own well-being.

Therefore, UCW unduly burdens women due to the existence of underlying gendered social norms that expect women to play an active role in the domestic sphere. However, variations of the expectations of the role of women can be seen across ethnic and rural-urban divides. Gender inequalities in UCW that views care work as a female prerogative must be addressed to achieve satisfactory strides in female participation in the labour force. Furthermore, access to safe and affordable care services is paramount in reducing this excessive caregiver burden placed on women. Social protection and welfare schemes too have to be strengthened to break the cycle of poverty and provide assistance to persons with disabilities and vulnerable families in addressing women's unpaid care burden.

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பெண்கள் மற்றும் ஊடகக் கூட்டமைப்பு
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