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Deepening Vulnerability: COVID -19 and Disability

Binendri Perera

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COVID -19 and Disability**

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**International Centre for Ethnic Studies
2023**

Deepening Vulnerability: COVID-19 and Disability

@ 2023 International Centre for Ethnic Studies (ICES)

2, Kynsey Terrace, Colombo 8, Sri Lanka

E-mail : admin@ices.lk

URL : www.ices.lk

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Deepening Vulnerability: COVID-19 and Disability

by

Binendri Perera*

* Binendri Perera is a D.Phil. candidate in law at the University of Oxford. She is on study leave from her position at the Department of Public & International Law at the Faculty of Law of the University of Colombo. She read for her LL.M. at Harvard Law School, where she was a Cogan Scholar (2018/19). She completed her LL.B. at the Faculty of Law of the University of Colombo. Her main research interests are constitutional law, feminist legal theories, pro-democracy movements, economic, social, and cultural rights, and the rights of marginalised groups.

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Binendri Perera

Table of Contents

Executive Summary	xi
1. BACKGROUND	1
1.1. Trajectory of Sri Lanka’s Covid-19 response.....	1
1.2. Status of persons with disabilities.....	5
1.2.1. Outdated legal framework and unimplemented policies	6
1.2.2. Socio-legal dynamics that marginalise persons with disabilities	7
1.2.3. Aggravation of the marginalisation due to war	10
1.2.4. Intersectional identities and multiplication of marginalisation for women with disabilities	12
2. METHODOLOGY AND RESEARCH SAMPLE.....	13
3. SYSTEMIC MARGINALISATION FACED BY PERSONS WITH DISABILITIES	18
3.1. Diversity of disability as a hierarchy of inequality.....	18
3.2. Disability as affecting family economic and social status.....	20
3.3. Geographical and class-based inequality resulting from unequal development.....	21
3.4. Lack of access to physical environment	22
3.5. Limited opportunities for employment and the challenges in employment.....	23
3.6. Systemic lack of access to education	24
3.7. Struggles of reliance on insufficient social welfare schemes	26
3.8. Marginalisation in access to health.....	27
3.9. Weak access to justice.....	30
3.10. Inequities in provision of administrative services	30
3.11. Community engagement and lack of political engagement.....	31
3.12. Attitudinal barriers.....	32
3.13. Women with disabilities and women caregivers for persons with disabilities.....	34

4. COVID-19 RESPONSE AND AGGRAVATION OF VULNERABILITY EXPERIENCED BY PERSONS WITH DISABILITIES.....	36
4.1. Covid-19 as a ‘humanitarian emergency’	36
4.2. Impact of health and safety regulations.....	36
4.2.1. Requirement to maintain one-meter to two-meter distance in public places	36
4.2.2. Quarantine camps	37
4.2.3. Hand sanitising/ hand washing stations	38
4.2.4. Requirements to use masks and use sanitisers	38
4.2.5. Lockdowns and curfews	39
4.2.6. Access to information on health guidelines.....	40
4.3. Access to essential goods and services	41
4.3.1. Food.....	41
4.3.2. Medicine and health services	42
4.3.3. Assistive devices	43
4.3.4. Sanitary items.....	44
4.3.5. PCR tests	44
4.3.6. Covid-19 vaccine.....	45
4.3.7. Transport.....	45
4.4. Loss of income due to pandemic response.....	46
4.5. Governmental social welfare schemes	47
4.6. Ethnic discrimination during the pandemic.....	48
4.7. Education during the pandemic	48
4.8. Privatisation of care of persons with disabilities	50
4.9. Corruption in distributing Covid-19 relief	50
5. THE ROLE PLAYED BY THE INSTITUTIONAL STAKEHOLDERS.....	52
5.1. The state institutions	52
5.1.1. Institutions at the centre.....	52
5.1.2. The police	54
5.1.3. Central institutions at the local level	54
5.1.4. Provincial Councils and local government authorities.....	56
5.2. Non-governmental organisations (NGOs).....	56

5.3. Organisations of persons with disabilities (DPOs).....	57
5.4. International organisations.....	58
6. RECOMMENDATIONS.....	59
6.1. Urgent actions.....	59
6.2. Actions for systemic transformation.....	60
6.2.1. Constitutional.....	60
6.2.2. Legislative.....	61
6.2.3. Executive.....	61
6.2.4. Financial.....	62
6.2.5. Administrative.....	62
6.2.6. Human Rights Commission and Ombudsman.....	64
6.2.7. Commission to Investigate Allegations of Bribery or Corruption.....	65
6.2.8. Provincial Councils and local government authorities.....	65
6.3. Themes for future research.....	65
CONTRIBUTORS.....	66

Executive summary

Sri Lanka's Covid-19 response started out in a militaristic style with vigorous contact tracing and quarantine camps maintained by the armed forces. But the government was not so vigilant in handling the second wave of the pandemic that started in late 2020 and the Covid cases peaked in 2021. The government's main response to the public health emergency was to impose health guidelines and keep the country in lockdown. The government also commenced the Covid-19 vaccine rollout in 2021. The aim of this report is to cast the spotlight on how these events were experienced by the most marginalised within Sri Lanka's unequal society, analysing the vulnerability of persons with disabilities.

Sri Lanka's persons with disabilities are systemically marginalised due to the outdated legal framework and unimplemented policies. Even though Sri Lanka ratified the United Nations Convention on Rights of Persons with Disabilities (CRPD) in 2016, the parliament has still not passed enabling legislation giving effect to these rights. National Policy on Persons with Disabilities and the Accessibility Regulations 2006 and 2009 are limited to paper. The government treats persons with disabilities solely as a welfare concern, thus placing them within the purview of the Department of Social Services as recipients of aid. Due to the inaccessible physical environment and stereotypical attitudes that persons with disabilities are incapable, many persons with disabilities and their families are in poverty. War-affected persons with disabilities, women with disabilities, and persons with disabilities from ethnic minorities face intersectional discrimination that further marginalises them. This report analyses how their situation is further complicated by the Covid-19 pandemic that is immediately followed by the economic crisis.

This report records the narratives of 33 persons with disabilities and 1 medical practitioner. These interviewees represent all nine provinces. They are living with diverse disabilities, face various socioeconomic conditions, and represent diverse ethnicities, religions, and languages.

According to the CRPD, disability results from interactions between impairments and the external environment, specifically infrastructure and attitudes that are indifferent and/or hostile towards these impairments. The interviews exposed the systemic nature of the marginalisation faced by persons with disabilities. Persons with disabilities are a heterogenous community who experience different types of

impairments in sight, hearing, mobility, and in terms of psychosocial engagement. These impairments are caused at different periods of life due to natural causes, accidents, and war. Since these different groups of people interact with the external environment in varying ways, there are gradations of marginalisation even among persons with disabilities. Effects of disability are experienced by the families alongside persons with disabilities. Family members grapple with disability as caregivers, providers, and dependents.

Persons with disabilities in Sri Lanka have to navigate geographical inequalities of development. Thus, persons from urban areas had better access to facilities than persons with disabilities from more rural areas and estates. Even among the persons in these different areas, persons with disabilities faced further inequality in terms of their class. For example, persons with disabilities from urban poor communities were deprived of access to all education and thereby, had no qualification whatsoever to engage in any employment. The lack of access to the physical environment and public places, such as banks and shops, severely limited the public participation and autonomy of persons with disabilities.

Persons with disabilities lacked access to inclusive education due to the school system that prioritises competition. A majority of persons with disabilities were engaging in home-based self-employment and relied on social welfare schemes such as the disability allowance for low-income persons with disabilities and Samurdhi. Even the persons who were in formal employment had to contend with discrimination and hostile, indifferent attitudes.

In accessing healthcare, persons with disabilities were disproportionately affected by the lack of accessible infrastructure, medical negligence, and lack of access to information. They faced marginalisation in access to justice due to delays and litigation costs. Since the public officials were person-focused in terms of serving the people who are friendly with them, most marginalised persons with disabilities faced exclusion. Women with disabilities endured added vulnerability due to safety concerns due to the prevailing gender-based violence and sexual harassment in public.

This systemic marginalisation made persons with disabilities extremely vulnerable during the pandemic. Covid-19 was a humanitarian emergency that affected persons with disabilities to such an extent that they were unable to recover on their own.

However, the government did not take the concerns of persons with disabilities into account in designing and implementing the Covid-19 response. Interviewees elaborated on the multiple ways in which the government's Covid-19 response marginalised them.

Covid-19 health guidelines further marginalised persons with disabilities in public places. Deaf persons and persons with psychosocial disabilities found information on changing health guidelines and lockdowns difficult to comprehend. Persons with disabilities were disadvantaged by the requirement to social distance in a physical environment that was inaccessible to them without the support of a third party. Muslim persons with disabilities from areas that were initially isolated faced intersectional discrimination. The quarantine camps did not provide facilities to accommodate persons with disabilities. Hand sanitising and handwashing stations in public places were not disability friendly for wheelchair users and blind persons. The usage of masks and sanitisers was an additional cost for poverty-stricken persons with disabilities and their families. Lockdowns and curfews resulted in a loss of income for many persons with disabilities who had to rely entirely on the social welfare of the government, non-governmental organisations (NGOs), and individuals. Therefore, responsibility for taking care of persons with disabilities affected by Covid-19 health guidelines was largely carried by private parties. However, the lack of regulation and coordination from the government diminished their effectiveness. In certain instances, governmental officials engaged in corruption by stealing the assistance provided for persons with disabilities.

Persons with disabilities struggled with access to their most basic needs, such as food, medicine and health services, assistive devices, sanitary items, and transport. Additionally, PCR tests and Covid-19 vaccines were not equally accessible. Persons with disabilities were especially cautious in taking the vaccine due to the fear of side effects that would undermine their health conditions.

The report also analyses the interviewee comments on the role of various institutional stakeholders during the pandemic. Sri Lanka is a unitary state with devolved powers to the provinces and local government authorities. The central government did not take into account the interests of persons with disabilities in designing or implementing the Covid-19 response. Continuing its usual charity-based approach towards persons with disabilities, the government gave two additional payments of Rs. 5000 and distributed essential items in several areas.

But this was not at all sufficient to sustain persons with disabilities during months-long lockdowns and travel restrictions that were in place for most of 2020 and 2021. Central governmental officials at the local level also failed to transcend beyond distributing charity towards empowering persons with disabilities. Furthermore, their person-focused service left the most marginalised persons in dire conditions. Interviews also revealed that the police in several areas implemented the curfews and health regulations in an unprofessional manner without regard for persons with disabilities. Provincial Councils were not elected during this period. Municipal Councils coordinated the distribution of dry rations at the local levels.

The NGOs and international organisations also contributed by providing persons with disabilities with essential items. However, their efforts would have been more productive had they received coordination from government officials to reach the neediest persons with disabilities in a sustained manner.

The report proposes that immediate and long term actions are required to respond to the situation of persons with disabilities who are affected by the pandemic measures of the government. Urgent actions are required to provide assistance for persons with disabilities who are without an income and who are struggling to revive their meagre sources of income. These actions must target firstly, to support the persons with disabilities to generate an income based on their existing skills and secondly, support persons with disabilities who are unable to earn a living.

Systemic transformations are required in the constitutional, legislative, executive, financial, and administrative spheres to eliminate discrimination against persons with disabilities. The central government, Provincial Councils, and local authorities must uphold the rights of persons with disabilities and strive for disability inclusive development. These actions must be overseen by the parliament, the president, and the fourth branch institutions such as the Human Rights Commission and Commission to Investigate Allegations on Bribery and Corruption.

1. BACKGROUND

Part I of this section provides context to the effects of the Covid-19 pandemic in Sri Lanka by tracing its trajectory in the country from 2020 onwards and highlighting the key decisions taken (and not taken) at the national level. Part II of this section provides context to the situation of persons with disabilities in Sri Lanka by summarising the structural, multi-layered discrimination that they face based on the existing literature.

1.1 Trajectory of Sri Lanka's Covid-19 response

The Covid-19 pandemic hit Sri Lanka in early 2020 with the country going into a lockdown immediately in March. This was only months after President Gotabhaya Rajapaksa was elected as the executive president to ensure national security against terrorist attacks. He used the same militarised approach to respond to the pandemic.¹ President appointed task forces to maintain the supplies, manage the spread of the virus, and then for the vaccine rollout, involving the armed forces in all these processes.² The parliament was dissolved by the president in February 2020 and the president refused to reverse the gazette. Even though he could not impose a curfew using the Public Security Ordinance as a result, the Supreme Court refused to intervene.³ This set the precedent for the executive to function without checks from either the legislature or the judiciary on the justification that this was an emergency.

The media announced restrictions on the movement called 'curfew, quarantine, police curfew and quarantine curfew.'⁴ These restrictions affected the country's tourism, construction, and transport.⁵ The Centre for Equality and Justice has found

¹ Binendri Perera, Niro Kandasamy, Karen Soldatic, 'Sri Lanka: Militaristic Enforcement and its effect on Disability' in Nichole Georgeou and Charles Hawksley, (eds.), *State Responses to COVID-19: a global snapshot at 1 June 2020* (Western Sydney University, Humanitarian and Development Research Initiative 2020) 74.

² Centre for Policy Alternatives, 'Legal and Policy Issues related to the COVID-19 Pandemic in Sri Lanka (December 2021) 6-7.

³ See, Binendri Perera, Niro Kandasamy, Karen Soldatic, 'Disability Exclusion during the Coronavirus Pandemic (COVID-19) in Sri Lanka' (2020) 1 University of Colombo Review 48.

⁴ Centre for Policy Alternatives (n 2) 8.

⁵ The World Bank, 'Economic and Poverty Impact of COVID-19' (2021) <<https://thedocs.worldbank.org/en/doc/15b8de0edd4f39cc7a82b7aff8430576-0310062021/original/SriLanka-DevUpd-Apr9.pdf>> accessed on 25 January 2023.

that the lockdown has increased instances of domestic violence in all districts.⁶ But the executive did not clarify the legal basis for these restrictions and they were implemented inconsistently.⁷ Simultaneously the president also implemented a compulsory cremation policy for all deaths caused by covid despite this being discriminatory towards the Muslim minority who bury their dead.⁸ These forced cremations included an infant and a woman who allegedly did not die from covid.⁹ Even though the cited reason of contamination of groundwater was ruled out by the World Health Organisation and pressure from the United Nations experts to revise the policy,¹⁰ amendments did not come until February 2021.¹¹

The World Bank records that Sri Lanka's economy contracted by 3.6% in 2020 amidst covid restrictions.¹² But Sri Lanka managed to control the spread of covid to open the country and hold the parliamentary election by August 5th.¹³ Sri Lanka Podu Jana Peramuna won a two-third majority during this election and a mandate to further relax the constitutional checks and balances by Twentieth Amendment to the Constitution.¹⁴ Meanwhile, covid resurfaced by September 2020 through clusters in garment factories.¹⁵ This further affected the country's apparel industry.¹⁶

⁶ Kamanthi Wickremasinghe, 'Domestic violence: A crisis in the age of pandemic' (11 December 2022) <<https://www.dailymirror.lk/press-releases/Domestic-violence-A-crisis-in-the-age-of-the-pandemic/335-250192>> accessed on 25 January 2023.

⁷ Centre for Policy Alternatives (n 2) 8.

⁸ Human Rights Watch, 'Sri Lanka: Forced Cremation of Muslims Discriminatory' (18 January 2021) <<https://www.hrw.org/news/2021/01/18/sri-lanka-covid-19-forced-cremation-muslims-discriminatory>> accessed 25 January 2023

⁹ *ibid.*

¹⁰ *ibid.*

¹¹ The Hindu, 'Sri Lanka ends forced cremations of COVID-19 victims' (26 February 2021) <<https://www.thehindu.com/news/international/sri-lanka-ends-forced-cremations-of-covid-19-victims/article33940422.ece>> accessed 25 January 2023.

¹² The World Bank (n 5).

¹³ Asian Network for Free Elections, 'Covid-19 and Elections: 2020 Sri Lankan Parliamentary Election, 5 August 2020' (5 August 2020) <<https://anfrel.org/covid-19-and-elections-2020-sri-lankan-parliamentary-election-5-august-2020/>> accessed 28 January 2023.

¹⁴ Dinesha Samararatne, 'Sri Lanka's constitutional ping-pong: The 20th Amendment in historical perspective' (25 September 2020) <<https://www.himalmag.com/sri-lankas-constitutional-ping-pong-2020/>> accessed 28 January 2023.

¹⁵ Economynext, 'Brandix cluster passes 1,000 confirmed cases in Sri Lanka's biggest COVID-19 outbreak yet' (7 October 2020) <<https://economynext.com/brandix-cluster-passes-1000-confirmed-cases-in-sri-lankas-biggest-covid-19-outbreak-yet-74514/>> accessed 25 January 2023.

¹⁶ Subhangi MK Herath, 'Impact of the COVID-19 Pandemic on Women Garment Workers in Sri Lanka's Free Trade Zones' (FTZS) 9-12 <<https://www.undp.org/sites/g/files/zskgke326/files/migration/lk/SL-FTZ-Report.pdf>> accessed 25 January 2023.

By November 2020, Sri Lanka started to report an average of 4-5 deaths per week.¹⁷ This escalated to a community spread by June 2021 and the country was in lockdown and restrictions on inter-province travel for the most of the year.¹⁸ With the onset of delta variant, the number of new cases and deaths peaked in mid-2021. August 2021 reports the peak of community spread (9912 new cases) and deaths (5961 deaths).¹⁹ The country reopened in stages starting from October 2021 but faced the omicron variant in 2022.²⁰

On January 29, 2021, Sri Lanka began vaccinating its frontline workers and rolled out the doses to its citizenry based on age.²¹ However, the Centre for Policy Alternatives highlights the irregularities relating to vaccine procurement due to delays and mismanagement.²² Therefore the country had to rely heavily on donations of the Oxford AstraZeneca 'Covishield' vaccines through the COVAX facility to support countries through the pandemic and donations of Sinopharm from China.²³ The Centre for Policy Alternatives further summarises irregularities in vaccine rollout due to questionable risk prioritisation and lack of information available.²⁴ They further detail how the presidential fund for Covid-19 Healthcare

¹⁷ Google News, 'Covid-19 Statistics' (2023) <https://news.google.com/covid19/map?hl=en-US&mid=%2Fm%2F06m_5&gl=US&ceid=US%3Aen> accessed 25 January 2023.

¹⁸ Devana Senanayake, Janik Sittampalam, 'When Sri Lanka Lost Control of COVID (1 2022)' <<https://thediplomat.com/2022/03/when-sri-lanka-lost-control-of-covid/>> accessed 25 January 2023.

¹⁹ Google News (n 17).

²⁰ Chanaka Jayasinghe, 'Omicron replaces Delta as dominant COVID-19 variant in Sri Lanka' (25 January 2022) <<https://economynext.com/omicron-replaces-delta-as-dominant-covid-19-variant-in-sri-lanka-89906/>> accessed 25 January 2023.

²¹ Meera Sirinivasan, 'Coronavirus, Sri Lanka begins vaccine roll-out' (29 January 2021) <<https://www.thehindu.com/news/international/coronavirus-sri-lanka-begins-vaccine-roll-out/article33698328.ece>> accessed 28 January 2023.

²² Centre for Policy Alternatives (n 2) 26-28

²³ Unisef Sri Lanka, 'Partnership with Donors help to Strengthen Sri Lanka's COVID-19 Vaccination Rollout Through COVAX Facility' (18 March 2021) <<https://www.unicef.org/srilanka/press-releases/partnership-donors-help-strengthen-sri-lankas-covid-19-vaccination-rollout-through>> accessed 25 March 2023; Unisef Sri Lanka, 'Sri Lanka receives over 1.5 million doses of COVID-19 vaccines from COVAX' (15 July 2021) <<https://www.unicef.org/srilanka/press-releases/sri-lanka-receives-over-15-million-doses-covid-19-vaccines-covax>> 25 January 2023; President's Secretariat Sri Lanka, 'China donates another 1.6 million doses of Sinopharm to Sri Lanka' (27 July 2021) <<https://www.presidentsoffice.gov.lk/index.php/2021/07/27/china-donates-another-1-6-million-doses-of-sinopharm-to-sri-lanka/>> accessed 25 January 2023.

²⁴ Centre for Policy Alternatives (n 2) 28-29.

and Social Security titled 'Itukama' (set up on 23 March 2020) failed to maintain clear and transparent records, mismanaged the funds, and failed to utilise a majority of its funds in the pandemic response.²⁵

In 2022, Sri Lanka's situation was further strained by the economic crisis resulting from the executive's economic mismanagement. The country's economy shrank 8.4% in April-June 2022 quarter and 11.8% in July-September 2022 quarter.²⁶ According to the Central Bank, consumer price inflation which has been between 5% -6.5% from January 2020 to September 2021 records a sharp rise from thereafter.²⁷ September 2022 reports all-time high inflation of 73.7%.²⁸ The fuel crisis resulting from the currency crisis led to long hours of power cuts and long queues at petrol and diesel stations.²⁹ This further crippled the country's tourist and other sectors that were struggling to revive after being affected from the pandemic.³⁰

These crises led to mass protests starting in March 2022 and spanning to July leading to the resignation of the president and the election of a president by the parliament.³¹ Sri Lanka defaulted on its sovereign debts in June 2022 and sought assistance from the International Monetary Fund to restructure its debt. The Budget Speech for 2023 announces that the disability allowance will be reduced to half (from Rs. 5000/= to Rs.2500/=) for four months.³² This has a direct impact

²⁵ *ibid* 24-25.

²⁶ Uditha Jayasinghe, 'Sri Lanka's economy shrinks 8.4% amid fertiliser, fuel shortages' (15 September 2022) <<https://www.reuters.com/world/asia-pacific/sri-lankas-economy-shrinks-84-amid-fertilizer-fuel-shortages-2022-09-15/>> accessed 25 January 2023; Uditha Jayasinghe, 'Sri Lanka's economy shrinks 11.8% in second-worst quarterly performance' (15 December 2022) <<https://www.reuters.com/markets/asia/sri-lankas-economy-shrinks-118-q3-2022-12-15/>> accessed 25 January 2023.

²⁷ Central Bank of Sri Lanka, 'Consumer Price Inflation' (2022) <<https://www.cbsl.gov.lk/measures-of-consumer-price-inflation>> accessed 25 January 2023.

²⁸ *ibid*.

²⁹ Rehana Thowfeek, 'Tourism in Sri Lanka: One step forward, two steps back' (25 March 2022) <<https://www.aljazeera.com/economy/2022/3/25/hold-tourism-in-sri-lanka-one-step-forward-two-steps-back>> accessed 25 January 2023.

³⁰ *ibid*.

³¹ Binendri Perera, 'The People vs The President: The Sri Lankan People's Struggle to Reassert Constitutionalism' (Verfassungsblog 2022) <<https://verfassungsblog.de/the-people-vs-the-president/>> accessed 25 January 2023.

³² Ranil Wickremasingha, 'Budget Speech 2023' (14 November 2022) Annexure V, 40. The 2024 Budget proposes to increase the disability allowance from Rs. 5000/= to Rs. 7500/= and allocate further funds for cash transfers for persons with disabilities with low income. The implementation of these proposals is to be seen. Ranil Wickremasingha,

on persons with disabilities. The main focus of the report is on the pandemic. However, the report also makes occasional references to the economic crisis as its effects have compounded upon the effects of the pandemic for persons with disabilities interviewed.

1.2 Status of persons with disabilities

Sri Lanka has not updated statistics on persons with disabilities since 2012. Therefore, the researchers have to rely on outdated data to assess the prevalence of disabilities, demographics, and economic status of persons with disabilities. Campbell states that there are further concerns about the identification and categorisation of persons with disabilities and therefore, estimates Sri Lanka's disabled population to be between 5% to 20%.³³

According to the 2012 statistics, Sri Lanka reports 8.7% of persons with disabilities.³⁴ These people face disability mainly due to three reasons: medical conditions, accidents, and conflict-related. This means that about 34% of Sri Lanka's families are dealing with disability.³⁵ However, due to the inaccessible physical environment and hostile, indifferent societal attitudes,³⁶ persons with disabilities suffer from extremely poor social and economic conditions.³⁷ This section provides an overview of the status of persons with disabilities from the national level legal regime to the experiences of persons with disabilities within most marginalised communities at the grassroots level.

'Budget Speech 2024 - A Prelude to the Stable Future' <<https://www.treasury.gov.lk/api/file/ed037ac8-9727-4292-ae9b-edac08c7a314>> accessed 24 January 2024.

³³ Fiona Kumari Campbell, 'The Terrain of Disability Law in Sri Lanka: Obstacles and Possibilities for Change' in S Rao, M Kalyanpuram (eds), *South Asia and Disability Studies: Redefining Boundaries and Extending Horizons* (Peter Lang Publishers 2015) 78, 80.

³⁴ National Census of Population and Housing 2012 Final Report. Dept of Census and Statistics. <http://www.statistics.gov.lk/page.asp?page=Population%20and%20Housing>

³⁵ Counted based on the national household size of 3.5 in Padmani Mendis, Binendri Perera, 'The Disability Policy Brief for Law Makers, Administrators and other Decision Makers in Sri Lanka' (ICES 2019) 6.

³⁶ See the description of persons with disabilities in the Preamble of the CRPD.

³⁷ See, Padmani Mendis, Binendri Perera (n 35) 6-7.

1.2.1 Outdated legal framework and unimplemented policies

Despite the country having signed and ratified the CRPD in 2016, the country has not introduced enabling legislation to date. Sri Lankan Constitution 1978 does not expressly enshrine the rights of persons with disabilities apart from permitting the state to take measures to advance their interest in Article 12 (4) on right to equality. The Protection of the Rights of Persons with Disabilities Act, No. 28 of 1996 (as amended in 2003) continues to interpret disability in negative terms based on ‘deficiency in physical and mental capabilities’ and inability to function independently in their daily lives.³⁸ This definition has not been updated with the progressive definitions available in CRPD appreciating persons with disabilities as part of human diversity and disability as arising from barriers in the physical environment and hostile attitudes.³⁹

The main purpose of the Act is to establish the National Council for Persons with Disabilities (NCPD) and the National Secretariat for Persons with Disabilities (NSPD).⁴⁰ These two institutions have been continuously housed in the Ministry of Social Welfare (currently the State Ministry of Women, Child Affairs and Social Empowerment) reinforcing the charity-based approach towards persons with disabilities.⁴¹ The recognition of rights under the Act is limited to equality in recruitment to employment, admission to educational institutions and access to public places.⁴² Due to the failure of the legislature incorporate the CRPD, the broad range of rights to ensure non-discrimination, autonomy, independence, equality, and access for persons with disabilities have not been mainstreamed.⁴³ National Policy on Disability 2003 and the National Action Plan on Disability 2014 is better aligned with the CRPD, but are not implemented.⁴⁴

³⁸ Section 37 on interpretation.

³⁹ CRPD Preamble and Article 1.

⁴⁰ See, the Preamble, Part I, and Section 14 of the 1996 Act.

⁴¹ Dinesha Samararatne, Karen Soldatic, Binendri Perera, “Out of the Shadows’: War-affected Women with Disabilities in Sri Lanka – Final Report’ (LST 2018) 10-11.

⁴² Section 23. Section 24 provides a remedy by way of judicial action before the Provincial High Court set up through Article 154P of the Constitution of Sri Lanka 1978.

⁴³ For the principles to be upheld in promoting the rights of persons with disabilities see CRPD Article 3.

⁴⁴ Padmani Mendis, Binendri Perera (n 35) 8-10; Dinesha Samararatne, Karen Soldatic, Binendri Perera (n 41) 9.

Accessibility Regulations of 2006 and 2009,⁴⁵ setting details of access to public buildings and transport, is also not implemented even though the Supreme Court has declared this to be a violation of Article 12 (1) on right to equality in two cases: *Ajith Perera v Minister of Social Services* (2011)⁴⁶ and *Ajith Perera v Minister of Social Services* (2019).⁴⁷ *Ajith Perera (2019)* recognises that courts will take guidance from the UNCRPD as ‘soft law’ because Sri Lanka is a state party to this Convention even if the parliament has not enacted enabling legislation.

Additionally, *Gnei Junior Abbas v Director General of Pensions*⁴⁸ allows the caregiver sister to appear on behalf of her brother to argue for his right to equal protection of the law under Article 12 (1). The court holds that dependents who became disabled in the aftermath of the death of the pension receiver are entitled to receive the pension of the deceased according to the Widows’ and Orphans’ Pension Fund (Amendment) Act if the disability renders them incapable of earning a living. The court’s interpretation focuses on the condition of the person with a disability thus producing an outcome that upholds the rights of persons whose disabilities are so severe as to render them incapable of earning.

1.2.2 Socio-legal dynamics that marginalise persons with disabilities

Meekosha and Soldatic state that the UNCRPD’s approach to disability as ‘bodies *in* the social dynamics’ is Global North centric.⁴⁹ They argue that nuances of marginalisation faced by persons with disabilities in the Global South are clearer as ‘social dynamics *in* the body.’⁵⁰ This report takes a similar approach in exploring how the persons with disabilities experience marginalisation due to various socio-legal dynamics. Persons with disabilities in Sri Lanka face systemic discrimination reinforced over the years by legal, political, economic, social, and cultural frameworks. Even though there have been recommendations to take a multi-ministerial, multi-sectoral approach to mainstreaming the rights of persons

⁴⁵ Ministry of Social Welfare, Guidelines of making the built environment accessible to persons with disabilities, Gazette Number: 1, 467/15 (17.10.2006). Ministry of Social Welfare, Guidelines of making the built environment accessible to persons with disabilities, Gazette No. 1619/24 – (18.09.2009).

⁴⁶ SC FR No 221/2009 SC Minutes 27 April 2011.

⁴⁷ Services, SC FR Application No. 273/2018 (18.04.2019)

⁴⁸ (2012) Sri LR 197.

⁴⁹ Helen Meekosha, Karen Soldatic, ‘Human Rights and the Global South: the case of disability’ (2011) 32 Third World Quarterly 1385.

⁵⁰ *ibid.*

with disabilities, the subject of disability has continued with the Ministry of Social Welfare (or its equivalent labelled Ministry of Social Empowerment).⁵¹ Accordingly, budgetary allocations have also focused primarily on welfare schemes (such as disability allowances and other lump sum payments for constructing houses and facilitating the education of children with disabilities).⁵²

Currently, the Ministry of Social Empowerment is with the president with a state minister also holding the same portfolio. While the president can play a significant role in overseeing a multi-ministerial, multi-sectoral, multi-level approach to upholding the rights of persons with disabilities,⁵³ there has been no such substantive adoption of a rights-based approach. Therefore, the president only holds the subject just as any other cabinet minister would. The labelling of the ministry as ‘social empowerment’ and placing it the subject with the president, therefore, are superficial changes that had not brought any substantive transformations towards upholding the rights of persons with disabilities.

Sri Lankan education system does not provide inclusive education for persons with disabilities.⁵⁴ Schools that prioritise the competitive exam-oriented studying environment neglect the education of children with disabilities.⁵⁵ Liyanage elaborates how teachers lack the training to educate children with disabilities and how such children are marginalised in special education units.⁵⁶ Such segregation reinforces their stigmatisation by abled students and teachers.⁵⁷ As a result, even though children with disabilities enrol at schools they also drop out in high rates.

⁵¹ Dinesha Samararatne, Karen Soldatic, Binendri Perera (n 41). See also, Azra Jiffry, Binendri Perera, ‘Status of Persons with Disabilities in Sri Lanka’ in Dinesha Samararatne (ed), Sri Lanka: State of Human Rights 2017 (LST 2017) 111.

⁵² ‘Budget Estimate 2021 – Sri Lanka’ 131 <<https://www.treasury.gov.lk/api/file/fd8b2db1-9046-4075-b368-0949569e2862>> accessed 26 January 2023; Department of Social Services ‘Applications/ Formats’ (2023) <https://www.socialservices.gov.lk/web/index.php?option=com_content&view=article&id=43&Itemid=154&lang=en> accessed 26 January 2023.

⁵³ Padmani Mendis, Binendri Perera (n 35) 19.

⁵⁴ Azra Jiffry, Binendri Perera (n 50) 123-124.

⁵⁵ Chandani Liyanage, ‘Inclusivity of children with disabilities and downsides of welfare-oriented service delivery system in Sri Lanka with special reference to rural areas in Galle district’ (2022) 3 University of Colombo Review 163; Azra Jiffry, Binendri Perera (n 50) 124.

⁵⁶ *ibid.*

⁵⁷ *ibid.*

Attendance of persons with disabilities is at the extremely low percentage of 2.6%.⁵⁸ While there is a special intake for ‘blind and differently abled candidates’ at the university level, this is limited to the Arts, Commerce, Biological Science, and Physical Science.⁵⁹ An additional barrier that persons with visual impairment face in education is access to copyrighted books. Sri Lanka acceded to the Marrakesh treaty to Facilitate Access to Published Works for Persons who are Blind, Visually Impaired, or Otherwise Print Disabled 2013 in 2016. The Intellectual Property Act, No. 36 of 2003 was only amended in 2021 to recognise exceptions for persons with print disabilities, and actions are required to make works available in an accessible format.⁶⁰

In terms of vocational education, while there are several state authorities at the national level providing and facilitating vocational training, they do not mainstream training the persons with disabilities. These include the Tertiary and Vocational Education Commission, the Vocational Training Authority, and the University of Vocational Technology of the Ministry of Education, which function at the national level with decentralised units. It is only the Department of Social Services that provides targeted vocational education for persons with disabilities, but they only operate 9 Vocational Training Centres across the country.⁶¹ This number is not sufficient to provide training for persons with disabilities. Additionally, Science and Technology divisions within the Divisional Secretariats also facilitate and coordinate vocational training for persons, including persons with disabilities, in the area. But their impact has been limited.

The lack of access to education significantly limits employment opportunities for persons with disabilities. These opportunities are further narrowed by the physical environment that denies them access, ranging from public transport to public

⁵⁸ Azra Jiffry, Binendri Perera (n 50), quoting from 2012 Statistics 125.

⁵⁹ University Grants Commission of Sri Lanka, Admission to Undergraduate Courses of the Universities in Sri Lanka (Academic Year 2021/2022) 162.

⁶⁰ Act, No. 8 of 2021, Section 12A.

⁶¹ 3 Centres are in Western Province (Gampaha District), 2 are in Central Province (Kandy District), 1 in Southern Province (Hambantota District), 1 in North Western Province (Puttalam District), 1 in Sabaragamuwa Province (Rathnapura District) and 1 in Eastern Province (Trincomalee District). The 10th Vocational Training Centre is scheduled to be opened in the Eastern Province (Batticaloa District). Department of Social Services, ‘Vocational Training for Handicapped Persons’ (2022) <https://www.socialservices.gov.lk/web/index.php?option=com_content&view=article&id=22&Itemid=131&lang=en> accessed 26 January 2023.

buildings and spaces to public information. Additionally, persons with disabilities face stigma and negative stereotypes from employers and society. Even though the state has set a quota for persons with disabilities in public sector employment,⁶² systemic discrimination that these persons face is such that they are unable to take its benefit. According to 2012 statistics, only 41.1% of persons with disabilities are in employment.⁶³ Consequently, many persons with disabilities and their families live in perpetual poverty.⁶⁴

In terms of participation in democracy through voting, the Elections (Special Provisions) Act, No. 28 of 2011 provides for special procedures of voting for persons with disabilities. However, instead of facilitating digital voting for persons with visual impairment, the Act provides for them to vote through an ‘accompanying person.’⁶⁵ This undermines the secrecy of their ballot and thereby, their freedom of expression.⁶⁶ Representation of persons with disabilities in parliament has been almost nil. There has been one person with disabilities in the parliament in 2017,⁶⁷ but the parliament elected in 2020 does not have any person with a disability.

1.2.3 Aggravation of the marginalisation due to war

The number of persons with disabilities increased in Sri Lanka due to physical and cognitive disabilities caused due to the civil war.⁶⁸ Persons with disabilities who navigated the ‘LTTE-controlled conflict zones were then trapped in the closed camps for internally displaced post-2009.⁶⁹ The poor conditions and lack of accessible washrooms within these camps were especially disadvantageous for persons with disabilities.⁷⁰ Both the Report of the Lessons Learnt and Reconciliation and the National Policy on Reconciliation and Coexistence 2017 recognise disabled persons as a vulnerable group.⁷¹ The Report states that persons with disabilities

⁶² Azra Jiffry, Binendri Perera (n 50) 127.

⁶³ *ibid.*

⁶⁴ PHT Kumara, Dileni Gunawardena, ‘Disability and poverty in Sri Lanka: A household level analysis’ (2017) 40 *Sri Lanka Journal of Social Sciences* 53-69.

⁶⁵ Sections 2, 5, 8, 11, 14.

⁶⁶ Azra Jiffry, Binendri Perera (n 50) 128.

⁶⁷ *ibid.*

⁶⁸ Fiona Kumari Campbell (n 33).

⁶⁹ Report of the OHCHR Investigation on Sri Lanka OISL Report (16 September 2015) 208.

⁷⁰ *ibid* 213.

⁷¹ Report of the Commission on Lessons Learnt and Reconciliation (November 2011)

faced difficulties in even attending discussions on transitional justice because of the inaccessible environment.⁷² The LLRC Report highlights that urgent support is required for breadwinners who have become disabled as a result of war and notes that disability has ‘a serious economic impact on the survival of the family.’⁷³ *Reparation Policies and Guidelines 2021* also identifies persons with disabilities as a vulnerable category that must receive priority in individual reparations.⁷⁴

The Consultation Task Force Report on Reconciliation Mechanisms 2016 records how the persons who have become disabled due to war struggle to cope with their trauma and disability.⁷⁵ The CTF Report categorises persons with disabilities as a group in need of immediate reparations.⁷⁶ Whereas the Sri Lankan government established an Office of Reparations through the Office of Reparations Act of 2018, persons with disabilities are yet to receive such reparations.⁷⁷ Among such persons with disabilities, disabled soldiers have received facilities in the aftermath of war, but they face segregation in the villages constructed specifically for them and their families.⁷⁸ Meanwhile, the disabled ex-combatants face discrimination, surveillance, and stigma in the post-war context.⁷⁹ Samararatne, Soldatic, and Perera in ‘Out of the Shadows’: War-affected Women with Disabilities in Sri Lanka – Final Report’ (2018) focus on experiences of women from Northern, North Western, North Central, Central, and Southern Provinces. This report highlights the particular experiences of persons whose disabilities were caused by the war and fatigue with engaging in processes for transitional justice without achieving any substantial outcomes.⁸⁰

(LLRC Report) 346; National Policy on Reconciliation and Coexistence Sri Lanka (2017) 6-7.

⁷² LLRC Report (n 70) 189. Reiterated in Final Report of the Consultation Task Force on Reconciliation Mechanisms (November 2016) (CTF Report) 116-117.

⁷³ LLRC Report 350 (n 70) 189-190.

⁷⁴ *Reparation Policies and Guidelines (2021)* 24 <http://www.reparations.gov.lk/web/images/2021/Policy_and_Guidelines_final.pdf> accessed 31 January 2023.

⁷⁵ CTF Report (n 71) 66.

⁷⁶ *ibid* 36.

⁷⁷ Binendri Perera, ‘Learning about rights, claiming a gendered-disability identity: the role of reparations and gendered-disability justice,’ Dinesha Samararatne and Karen Soldatic (eds.), *Women with Disabilities as Agents of Peace, Change and Rights: Experiences from Sri Lanka* (Routledge 2020)

⁷⁸ Azra Jiffry, Binendri Perera (n 50) 134-135.

⁷⁹ *ibid*.

⁸⁰ Dinesha Samararatne, Karen Soldatic, Binendri Perera (n 41) 17-18, 20.

1.2.4 Intersectional identities and multiplication of marginalisation for women with disabilities

There are several studies from Sri Lanka that record the multiple marginalisation of women with disabilities. They highlight the grassroots level experiences of disability. Samararatne and Soldatic in 'Rural disabled women's social inclusion in post-armed conflict Sri Lanka' (2014) study the marginalisation of rural women with disabilities from the North Central Province. They state that while these women are encouraged and cared for within their families, they find it exceedingly difficult to participate in public due to inaccessibility to the physical environment, hostile attitudes, lack of access to education and healthcare, and inconsistencies in assistance from the state.⁸¹ They also note that women have borne a severe brunt of the armed conflict.⁸² Samararatne and Soldatic in 'Inclusions and exclusions in law: experiences of women with disability in rural and war-affected areas in Sri Lanka' (2015) highlight how the rural women with disabilities have weak general literacy and legal literacy and how the financial assistance provided by the state is conditional on following onerous procedures and insufficient.⁸³

Samararatne, Soldatic and Kandasamy in 'Peace, justice and disabled women's advocacy: Tamil women with disabilities in rural post-conflict Sri Lanka' (2016) and 'Southern gendered disability reflections: The everyday experiences of rural women with disabilities after the armed conflict in Sri Lanka' (2017) explore the marginalisation faced by Tamil women who were disabled due to civil war. These studies record the trauma of war that the women with disabilities recount as they try to live their daily lives, their simultaneous attempts to seek assistance and build cross-ethnic relationships of solidarity.⁸⁴ Kandasamy and Perera in 'Raging (e)motions' (2020) record the triple discrimination faced by a Muslim woman with disability from the Central Province, due to her disability, gender, and ethnic identity in the backdrop of growing islamophobia in Sri Lanka.⁸⁵

⁸¹ Dinesha Samararatne, Karen Soldatic, 'Rural disabled women's social inclusion in post-armed conflict Sri Lanka' (UNSW Australia and Social Scientists' Association, Sri Lanka, 2014) 7-12.

⁸² *ibid* 13-14.

⁸³ Dinesha Samararatne, Karen Soldatic, 'Inclusions and exclusions in law: experiences of women with disability in rural and war-affected areas in Sri Lanka' (2015) 30 *Disability & Society*, 764-68.

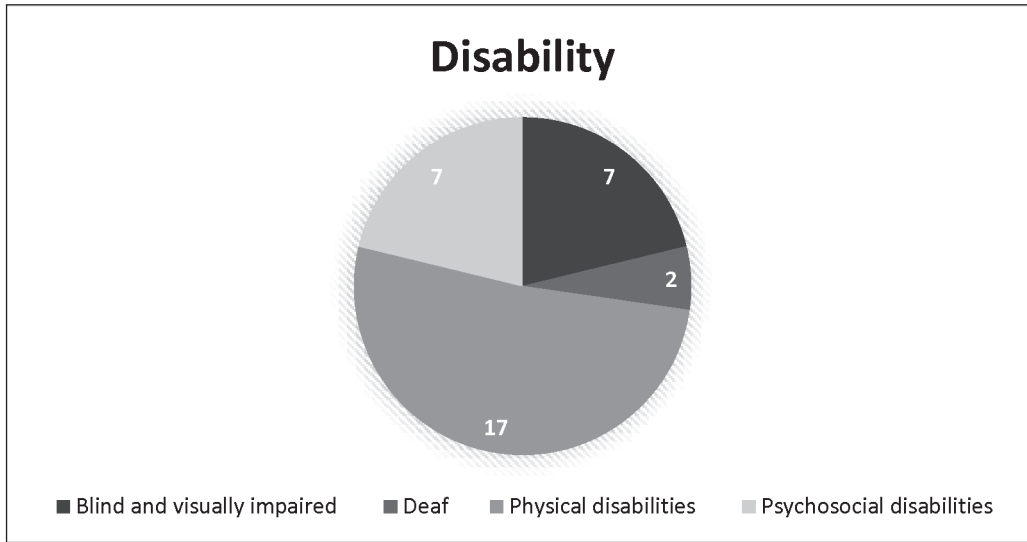
⁸⁴ Niro Kandasamy, Karen Soldatic & Dinesha Samararatne, 'Peace, justice and disabled women's advocacy: Tamil women with disabilities in rural post-conflict Sri Lanka' (2016) *Medicine, Conflict and Survival* 8-15.

⁸⁵ In Dinesha Samararatne and Karen Soldatic (eds.), *Women with Disabilities as Agents of Peace, Change and Rights: Experiences from Sri Lanka* (Routledge 2020).

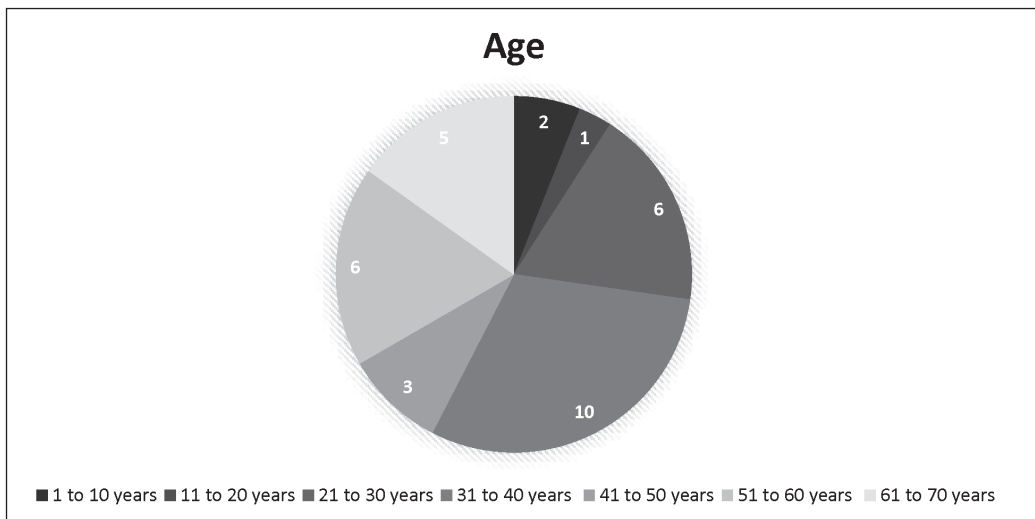
2. METHODOLOGY AND RESEARCH SAMPLE

This report is based on the narratives of 33 persons with disabilities and 1 medical practitioner treating persons with disabilities. Caregivers provided the interviews for deaf persons and persons with psychosocial disabilities (this included two children with disabilities). The researchers contacted the interviewees through the grassroots level NGOs and organisations of persons with disabilities (DPOs). 18 interviews were conducted in person and 16 interviews over the phone. The researchers commented that in-person interviews were more informative because interviewees opened up during the discussions. Because the researchers could observe the expressions of the interviewees, they could better ensure that the interviewees were comfortable in continuing to speak and also got more nuanced perspectives of their narratives. While phone interviews were more convenient in terms of travel costs and time, the researchers faced network issues at times and persons with disabilities required repeated explanations about the interview information. The semi-structured interviews were conducted after receiving the informed consent of the interviewees. 20 interviews were conducted in Sinhala and 14 interviews in Tamil. This report ensures the anonymity of the interviewees. The researchers selected interviewees from diverse experiences based on their disability, age, gender, ethnicity, religion, language, geographical location, level of education, and status of employment. The aim of this section was to record a range of experiences from a diverse group of persons with disabilities from different walks of life. However, the researchers faced difficulties in finding contacts for women with disabilities. One reason was that we received contacts of caregiver women, who were taking care of their disabled husbands, sons, or siblings. Another reason for this was that community leaders who were men tended to provide us with the contacts of men with disabilities. One community leader stated that they were hesitant to provide us with contacts of women with disabilities on the basis that they were 'lethargic and backward' and hence not suitable to be interviewed. This evidenced the multiple discrimination that women with disabilities faced within the local organisations.

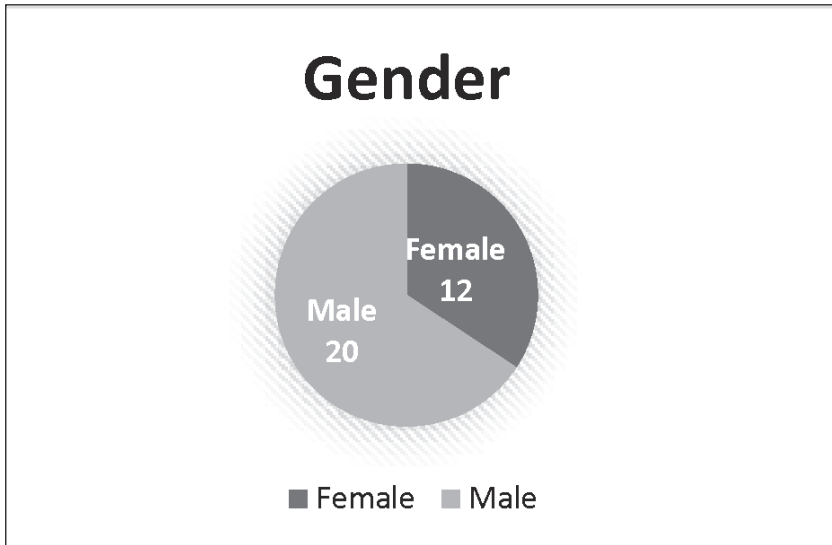
Interviewees based on disability:



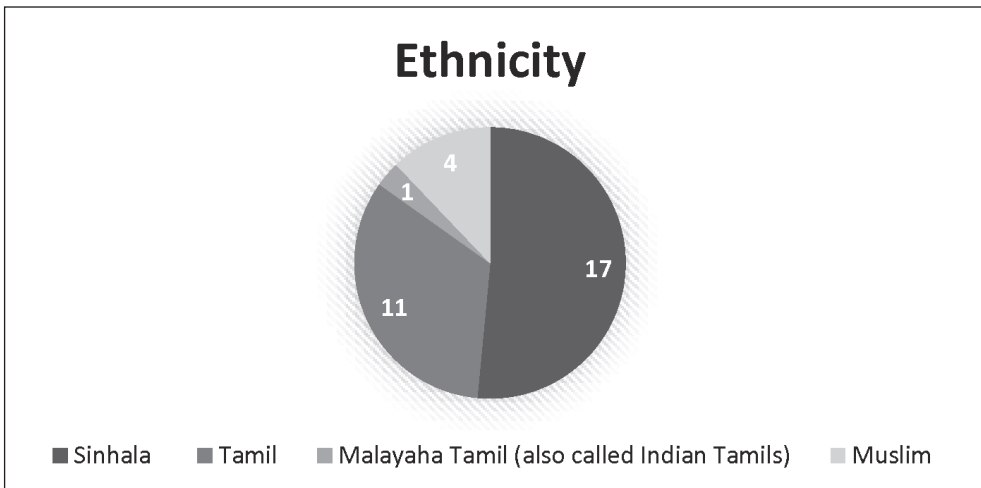
Interviewees based on age:



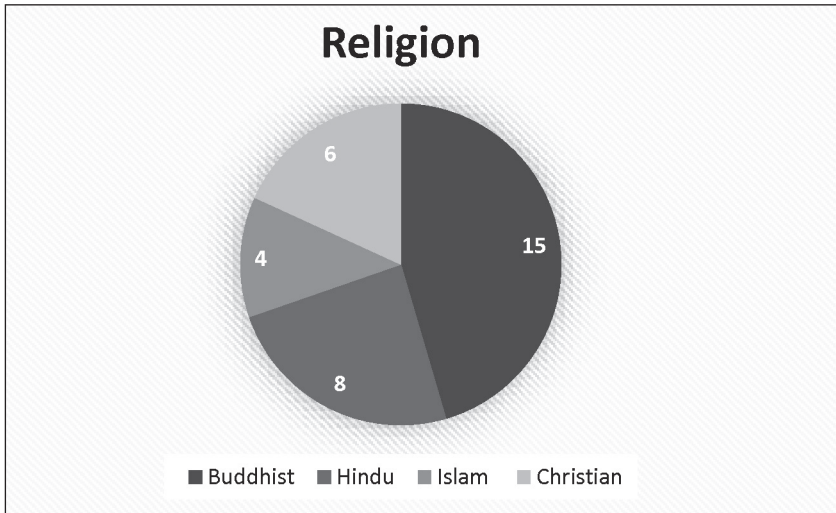
Interviewees based on gender:



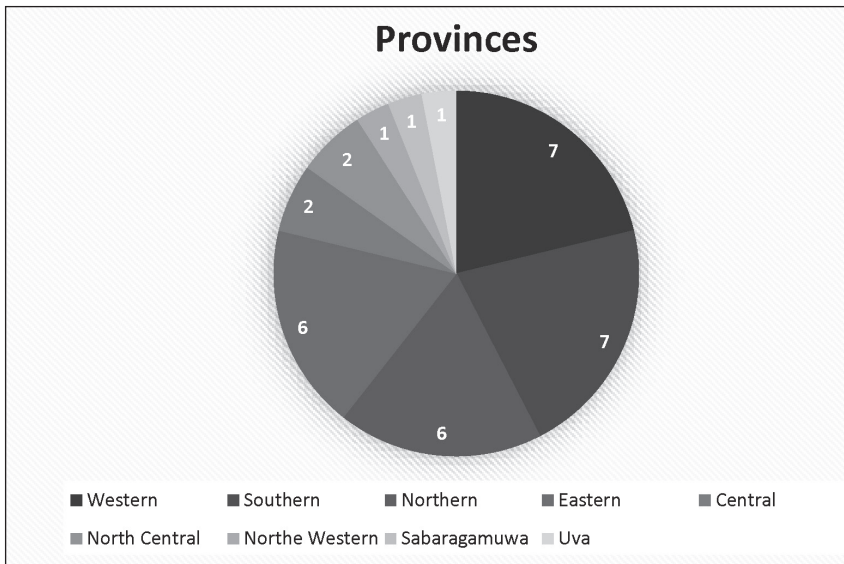
Interviewees based on ethnicity:



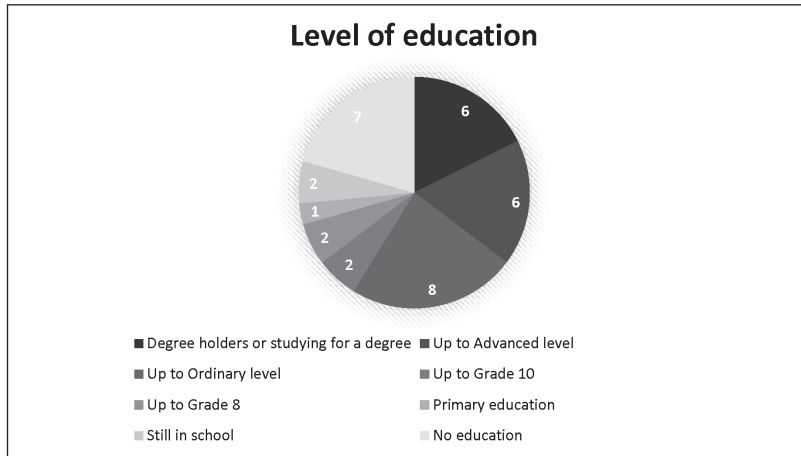
Interviewees based on religion:



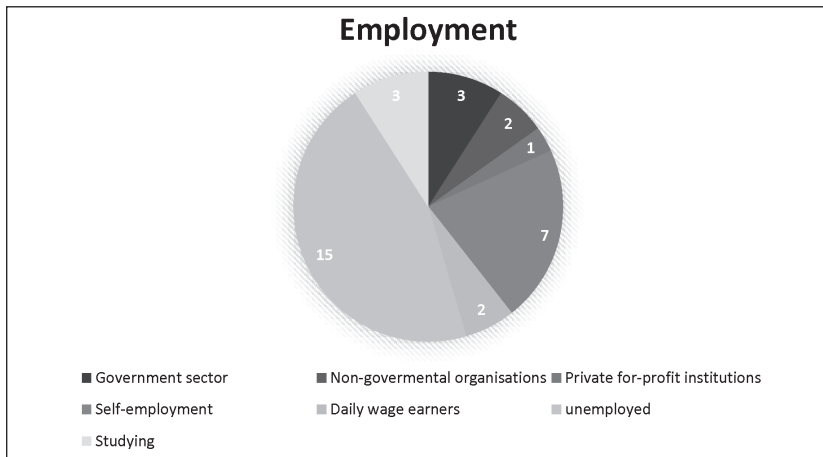
Interviewees based on provinces:



Interviewees based on level of education:



Interviewees based on the type of employment:



3. SYSTEMIC MARGINALISATION FACED BY PERSONS WITH DISABILITIES

‘If the government maintained better statistics of persons with disabilities, if the local officials had better records and awareness of the condition of persons with disabilities in their area, if we had overall better structures, we would have survived better during the pandemic. If these systemic factors are not fixed, persons with disabilities will not be able to survive another wave of covid.’

An interviewee from Western Province, Male, 30 years

Our interviews exposed a range of systemic factors that perpetuate the marginalisation of persons with disabilities. This section elaborates on how the systemic factors that exacerbated the vulnerability of persons with disabilities during the pandemic.

3.1 Diversity of disability as a hierarchy of inequality

Persons with disabilities face varying gradations of marginalisation based on the type and extent of their disability. Disabilities we encountered during the interviews include blindness and visual impairments, deafness, physical disabilities, and psychosocial disabilities. Subtypes of psychosocial disabilities included autism, hyperactivity, nervous disorders, and down syndrome. Among these types, the extent of the disability varied: from partially visually impaired to full visual impairment, from poor hearing to full hearing impairment, and from slow or bent walking to wheelchair users to being completely bedridden.

Out of these different types of disabilities, persons with visual impairments and physical disabilities had better access to educational and employment opportunities. For example, out of the three university graduates we interviewed two are visually impaired while the other is a wheelchair user. These are the disabilities that are immediately visible to the world.

In contrast, deaf persons and psychosocial disabilities have not had access to education or employment. All of these interviewees were under the care of their families and were restricted to their homes. They enjoyed little to no autonomy in

their lives. This was because persons with such disabilities cannot communicate with the abled community without training on both sides. The able persons, however, had not adjusted to communicate with these persons with disabilities, and facilities are not provided for the education, employment, and advancement of these persons with disabilities. Additionally, these disabilities were not immediately visible to the world and therefore, people lacked awareness about these persons with disabilities and their needs. As a result, deaf persons and persons with psychosocial disabilities lacked specific support systems and social security schemes focusing on their needs. Even in terms of visual impairments and physical disabilities, the more severe the disability more restricted the person was to their home. For example, a person who walks with a slight bent has been able to develop her business, establishing and maintaining links with governmental officials, NGOs, and other persons with disabilities to expand the business. Therefore, she was able to find buyers even during the pandemic through her local networks. In contrast, wheelchair users have not had the same outreach in engaging in their businesses. As a result, they struggled to buy the necessary materials and find customers, and their condition worsened during the pandemic.

However, persons with less severe disabilities faced issues in identifying their condition as a disability. This delayed and hindered them from receiving accommodations provided for persons with disabilities. For example, a person with low vision stated that he did not receive support from the Special Education Unit of his school until the latter part of his secondary education because he and his family did not think of his condition as a disability. He and his family did not receive support from any healthcare or educational institution in identifying his condition as a disability. However, he struggled to read the exam papers, which affected his educational progress. Moreover, he did not learn braille as he had partial sight. Because he did not use braille to sit the Advanced Level exam, he was not considered a person with a disability in the university intake. Therefore, the tendency to not consider less severe disabilities as disabilities places a heavy burden upon such persons to perform as if they are not disabled and denies them equal opportunities and accommodation.

There is further diversity among persons with disabilities based on the timing and cause of disability. While those who were disabled from birth or at a younger age struggle with access to opportunities persons who became disabled at a later age

struggle more with coming to terms with their disability. Many of them have given up their previous job because their disability does not allow them to perform the tasks of that job effectively. Their success in finding new employment depends on the extent to which their existing employable skills are not affected by the disability. For example, persons who have IT skills are able to use them even after they have become physically disabled. But switching to such a job is not easy due to the requirement of vacancies within a close range that the person can travel on a daily basis or the requirement of capital if they were to start a new venture on their own. Therefore, these people plunge into immediate poverty with the onset of disability. Persons who became disabled due to war, and people who are also either ex-combatants or female heads of households struggle with war-related trauma. Their vulnerability is worsened due to the multiple marginalisation they face.

3.2 Disability as affecting family economic and social status

While the experience of disability is particular to the individual there is an equally significant family impact from disability. Disability is connected to family in several ways. Firstly, when one person was disabled family members devote their time, energy, and resources to take care of that person. In such instances, the disabled child became the predominant concern of the mother. Caregiver mothers were perpetually anxious about who will take up the caregiving responsibilities once she passes away. This concern was heightened when the disabled child was a daughter. In households where the mother was not present or was not in good health, the siblings carried out the caregiver responsibilities.

Secondly, where the person with a disability was the head of the household the economy of the family was extensively undermined. These persons with disabilities failed to provide nutritious food and access to quality education for their children and lived with guilt due to this. This situation was worse in female-headed households with disabilities. Two single mothers we interviewed both stated that their families had to skip meals during the pandemic because they could not provide three meals. Thirdly, there were instances where several persons in the family were disabled. In households where both husband and wife were disabled, both the parents faced barriers in accessing employment and in providing their children with essential needs and basic education. In the instances where several siblings were disabled the non-disabled siblings and parents faced additional economic burdens in providing

for the disabled siblings. In situations where the caregivers have passed away, the disabled siblings were in dire conditions.

‘We have not worked at all because of our illness. During our childhood, our father looked after us by doing wage work. After he passed away, we suffered a lot. We have not got any assistance except Samurdhi from the government. The respondent cannot work since she cannot hear and talk. We are all afraid to go outside of the house. We always stay at home. We only go to the shop to buy groceries and temple on Fridays.’

Caregiver sister of a deaf person, Eastern Province

3.3 Geographical and class-based inequality resulting from unequal development

Sri Lanka is a developing country reporting an annual GDP growth rate of 3.3% in 2021.⁸⁶ Our interviews revealed inequalities of development and the resulting unequal distribution of facilities. Persons with disabilities bore disproportionate effects of this. Persons with disabilities who lived away from towns and main roads had less access to basic needs like food and medicine, employment, and networks (governmental institutions and community networks). For example, persons with disabilities from rural areas mentioned that they had to travel far for clinics or for work and the three-wheeler costs were unaffordable, especially during the pandemic. An interviewee described how he rode a bicycle extremely slowly with his weak legs enduring a lot of pain to reach the hospital. As a result, persons with disabilities cut down on seeking regular medical support. We interviewed two persons with disabilities who gave up on employment upon becoming disabled due to travelling costs. Therefore, the house had become a place of confinement for persons with disabilities even before the pandemic.

Conversely, an interviewee engaging in a small business in a rural area explained how the location of her house in front of a main road helped her with maintaining her business and establishing networks. She was in the process of constructing a small showroom for her products and the products of other persons with disabilities

⁸⁶ The World Bank, ‘Sri Lanka – data’ (2023) <<https://data.worldbank.org/country/LK>> accessed 27 January 2023.

in front of her house facing the main road. Similarly, an interviewee from an urban area also stated that he preferred his locality because despite the inaccessible physical environment many of the services were within close reach.

Yet, the benefits of access were not equally available to all persons with disabilities in urban areas. There were further inequalities resulting from the socioeconomic status of persons with disabilities which was connected to whether they belonged to the upper-class, middle-class, or poor communities. For example, the urban poor communities where we conducted interviews with persons with disabilities lived in extreme congestion without access to education, employment, or a clean and healthy environment. They could not afford to provide themselves with their daily necessities because they lacked the education and the qualifications to secure a stable job.

3.4 Lack of access to physical environment

Within the broader inequality of access to services, persons with disabilities in all provinces found their immediate physical environment inaccessible to them. This is a violation of a key principle of the CRPD that undermines many other rights for persons with disabilities.⁸⁷ An interviewee using a wheelchair explained the difficulties he faced in going to grocery stores, textile stores, and banks.

‘When I go to shops like textiles and banks, I ask one of my friends to accompany me. They help me by lifting me to those places. In some unavoidable situations, I go alone and some person who stands there helps me voluntarily.’

An interviewee from Eastern Province, Male, 32 years

An interviewee with low vision explained the difficulty of entering a bank and figuring out where the relevant forms are the difficulty of finding directions at hospitals, and the difficulties in navigating public transport. Another interviewee reported an instance where the police station was recording complaints on the second floor and therefore, persons with disabilities had to wait until an officer came down to make their complaint. This systemic inaccessibility worsened due to restrictions in accessing public buildings and transport during the pandemic.

⁸⁷ CRPD, Article 3 (f), Article 9.

3.5 Limited opportunities for employment and the challenges in employment

Lack of access to employment was at the core of the inescapable poverty and marginalisation that persons with disabilities face. Out of the persons with interviewed, three persons worked in government institutions, one person worked in the private sector and two persons worked for NGOs. Two persons were daily wage earners, seven were self-employed, and fifteen were unemployed – relying almost entirely on the disability allowance. Interviewees who were self-employed were from mainly Southern province with one interviewee based in the North Central province.⁸⁸ They engaged in sewing fishing materials, making ekel brooms, making coconut spoons, home gardening, sewing mats, making ornaments, knitting, repairing watches, and maintaining grocery shops.

The first of the barriers that persons with disabilities face in accessing employment was the lack of employable skills. The persons with disabilities who have not had access to education did not have the necessary qualifications and skills to access a range of employment opportunities. Even for persons with disabilities who had education and who worked prior to becoming disabled, their range of employment options was limited drastically upon becoming disabled. For example, two interviewees who become disabled due to accidents in later life had to give up the jobs that require them to handle vehicles. Then they had to develop employable skills that accommodated their disability. Therefore, home-based self-employment has been the main viable option for persons with disabilities.

Those who engage in self-employment faced challenges in acquiring skills for self-employment and in engaging in self-employment. One interviewee reported how the local administrative authorities provided vocational training for jobs he could not perform with his physical disability, such as being a security guard. The range of challenges that persons with disabilities faced in engaging in self-employment include finding the initial capital and materials, networking and linking up with potential buyers to sustain a market, and acquiring the management and financing skills required to maintain a business. Persons with disabilities have relied on the support of local-level governmental institutions, NGOs, community organisations,

⁸⁸ This could be because of the support these interviewees received from the local NGOs in the area that visited persons with disabilities and encouraged them to engage in community activities and provided them with training for self-employment.

and individuals (local and foreign) to receive support in carrying their self-employment forward.

One interviewee employed in the private sector explained the discrimination based on disability in the recruitment, continuance of employment, and receiving safe and healthy working conditions.⁸⁹ He stated that he was only selected when an individual was committed to giving an opportunity for persons with disabilities rather than through an institutional commitment to equality. He further explained how he had to leave his previous employment because his co-workers were hostile towards him in teaching work and because his slowness in learning was interpreted as lethargy. Co-workers in his current workplace provided him with accommodation to an extent, but the institution had not formally recognised his disability. As a result, he was constantly working extra hard, at times risking his health, to prove himself instead of receiving reasonable institutional accommodations for his disability.

3.6 Systemic lack of access to education

Education decides the range and quality of opportunities available for a person with a disability whose choices were severely restricted due to an inaccessible physical environment and hostile attitudes. The previous section elaborates how the persons with disabilities were limited to self-employment because they have not had access to basic and continuing education that would facilitate them to progress to be employed at government institutions and private commercial and non-commercial institutions.

The interviewees who have completed their tertiary education have managed to find employment that would enable them to live with independence, interdependence, and dignity. Interdependence refers to the various ways in which they support their families, their communities, and other persons with disabilities, and how they engage in advocacy for persons with disabilities. Only the person who received her degree during the pandemic was struggling to find employment

⁸⁹ Recognised in Article 27 (a) of the CRPD. The state is required to regulate the private sector to eliminate such discrimination against persons with disabilities in their workplaces.

because the government halted recruitment in 2021 and many private institutions restricted recruitment as well.⁹⁰

While Sri Lanka records high literacy rates, the Sri Lankan school system burdens the students with excessive study loads, ultra-competitive exams, and precarious employability through education.⁹¹ Whereas the schools have set up Special Education Units for children with disabilities, these do not promote inclusive education that would promote these children's dignity and facilitate their educational progress.⁹² One interviewee stated that the school neglected to provide staff for the Special Education Unit. He further described how he had to write the letters which the principal would then sign to receive the accommodations in facing the Advanced Level exam. These systemic weaknesses made it difficult for persons with disabilities to enjoy their right to education.

Access to education for persons with disabilities depended on the nature and severity of the disability. Persons with physical disabilities and visual impairments have been able to advance to tertiary education with family support. Persons whose disabilities were comparatively less severe – for example, the ability to walk with a bent or partial visual impairment- also had access to education. But the persons with psychosocial disabilities and deaf persons faced extreme marginalisation from education. None of the adult interviewees with these disabilities were able to complete their school education. Two children with psychosocial disabilities were receiving special needs education at a private school. But such a facility is not affordable to many parents and parents faced difficulties in accessing information about these facilities. A parent whose mother tongue is Tamil also stated the difficulties of finding schools that provide special needs education in Tamil or English because most of such schools are limited to Sinhala.

⁹⁰ Economynext, 'Sri Lanka to freeze hiring, halt new projects, target subsidies' (31 August 2021) <<https://economynext.com/sri-lanka-to-freeze-hiring-halt-new-projects-target-subsidies-85620/>> accessed 27 January 2023.

⁹¹ I. M. Kamala Liyanage, 'Education System of Sri Lanka: Strengths and Weaknesses' (2013) 126-127 <https://www.ide.go.jp/library/Japanese/Publish/Reports/InterimReport/2013/pdf/Co2_ch7.pdf> accessed 27 January 2023.

⁹² Chandani Liyanage (n 54).

3.7 Struggles of reliance on insufficient social welfare schemes

The majority of persons with disabilities we interviewed were either entirely or partially reliant on social welfare schemes. The two main payments that they received from the government were the Samurdhi allowance for families in poverty (Rs. 3000/=) and the disability allowance for low-income persons with disabilities (Rs. 5000/= until December 2022). One interviewee stated that she received public assistance (Rs. 1000/=). The interviewees raised several concerns about these social welfare schemes.

Firstly, three interviewees stated that Grama Niladari had not processed their applications for the disability allowance despite several attempts.

‘So far, I have not received the special allowance of Rs 5000 which have given to disabled persons. I have sent letters to the Grama Niladhari, asking for help many times. He used to say that if he can get help, he will inform me. But I have not got any help from him so far.’

An interviewee from the Indian Tamil community in Central Province, Female,
28 years

Secondly, the selection of persons with disabilities was arbitrary and unreasonable. For example, priority was given to persons with disabilities who have become disabled due to natural causes. Therefore, interviewees who were disabled as a result of an accident or war were either waitlisted or had not received satisfactory responses from the Grama Niladari for their area. This differentiation based on the cause of disability is problematic because persons with disabilities who became disabled in an accident or war faced specific challenges in coming to terms with their disability. Their health situation and limitation of employment opportunities made the transition particularly difficult. Persons who were disabled due to war as ex-combatants face further emotional trauma, governmental surveillance, and social stigma. Unequal treatment of these persons with disabilities in providing social security, therefore, resulted in heightened discrimination.

Another interviewee noted that the severity of the disability was not factored into eligibility for social welfare and this excluded more vulnerable persons with disabilities from receiving support.

'I saw that my disability was more serious than some of the students who had received the allowance. The authorities should allocate the social protection schemes based on the intensity of the disability because a person who is bedridden with a disability is in a much worse condition and has more requirements than a person who has lost his fingers.'

An interviewee from Uva Province, Male, 33 years

Thirdly, the payments given through the social welfare schemes were not sufficient. Disability allowance was provided only to one person per family, but this did not cover the needs of families with multiple persons with disabilities and children who were studying. Another interviewee stated that she was not eligible for Samurdhi or disability allowance because she was expected to be dependent on her father's pension that her old mother received, but the pension was not sufficient to cover the family's needs.

Fourthly, interviewees reported a lack of transparency in the distribution of the allowances. For example, there were delays and arrears in making payments, and even though the persons with disabilities signed the documents indicating receipt they were not given the payment.

3.8 Marginalisation in access to health

Sri Lanka provides free healthcare in state-run hospitals.⁹³ However, the lack of disability friendly infrastructure, cases of medical negligence, lack of information, lack of awareness and stigma on mental health conditions, and economic hardships disproportionately affect persons with disabilities.

The infrastructure of the hospitals did not facilitate independent access for persons with disabilities. An interviewee explained how people with low vision had to struggle to find directions in a government hospital due to the lack of disability friendly directions. Another interviewee stated that there were no specific counters

⁹³ Ramya Kumar, 'Public-private partnerships for universal health coverage? The free future of "free health" in Sri Lanka' (2019) 15 *Globalization and Health* < <https://globalizationandhealth.biomedcentral.com/articles/10.1186/s12992-019-0522-6> > accessed 27 January 2023.

for persons with disabilities in hospitals. Consequently, they had to wait hours in queues to get medicine. The inaccessible physical environment undermined the right to health of persons with disabilities.

Seven interviewees stated that their disability was a result of medical negligence. One interviewee reported how his disability was a result of an electric shock given to treat asthma. Despite the first dose leading to the disability, the hospital administered a second dose years later worsening the condition. Another interviewee stated that he was given double the required dose because another doctor gave the same medicine while the doctor in charge was on a call and that made him a wheelchair user.

‘As I was a small child, my parents did not have enough income to give treatment to this and my parents also did not take any action regarding their wrong treatment because they were illiterate and they feared to talk with doctors regarding this.’

An interviewee from Central Province, female, 28 years

The hospitals neglected in providing persons with disabilities with information regarding their disability which precludes them from taking the necessary steps toward recovery. An interviewee voiced his frustration due to the lack of improvement in his condition despite multiple visits to the hospital. He was especially concerned about whether the hospital was equipped to treat the severe wounds sustained during the war.

‘This terrible injury happened during the end of the war in 2009. Even though the injury has disappeared; the pain caused by it is still there. I have visited the clinic many times but it did not help me and these doctors are unable to give me a conclusive result. I’m still not clear whether it’s my physical condition or the injury or the doctors. Since this condition persists, I am completely avoiding this clinic as I don’t see any benefit to date. Now I am used to living with sickness and pain. In normal accidents, the bones are visible so it is very easy to put them together but we, as war victims, don’t have any bones for 2 to 4 inches so putting them together is a very difficult task.’

An interviewee from Northern Province, Male, 32 years

Another interviewee stated that healthcare personnel lacked professionalism in engaging with persons with disabilities. For example, when a person with a visual impairment asked for directions, they were asked to go ahead and find it. These experiences showed that healthcare personnel lacked the training to communicate with persons with disabilities and provide them with information. The instances of support emanated from personal acts of kindness and not from a professional commitment.

People tried to stifle or hide their mental health issues due to the lack of awareness and stigma and this led to long term suffering and disabilities. For example, one interviewee became disabled gradually through not receiving treatment for the depression he underwent after his child died in the war. Another interviewee who became disabled during the war refused to speak about their trauma. None of the interviewees spoke about receiving therapy even though they often spoke of the mental strain of being confined to the home and the feelings of incapacity they felt due to their disability. One interviewee had even attempted to commit suicide after the death of his child and the abandonment of his wife.

Economic hardships also became a barrier for persons with disabilities to access healthcare. Interviewees also explained how they would either require regular visits to the hospital to receive treatment that they cannot afford. In those situations, they chose to give up on pursuing such treatment even though this worsened their condition. For example, one interviewee wore his artificial leg only when necessary to avoid regular visits to the clinic. Another interviewee stated how an infection became a neurological disease and a permanent disability because the family could not afford treatment. Yet another interviewee reported that he needed to take surgery which would cost him an exorbitant amount and therefore, he has resigned to live with his current condition. When the government hospitals ran out of medication, persons with disabilities faced additional costs from having to buy them privately.

3.9 Weak access to justice

The judicial process in Sri Lanka is cumbersome due to the litigation costs and extreme delays.⁹⁴ Even though Legal Aid Commission has set up a Disabled Persons Desk,⁹⁵ persons with disabilities lacked information about this mechanism as well as the legal literacy and financial capacity to pursue long term litigation. The courts access to sign language interpretations and persons with disabilities had to incur exorbitant costs access services of these interpreters. Persons with print disabilities also had no access to accessible copies of legal documents and translations in braille. These burdens were severely disadvantageous to persons with disabilities.

An interviewee who was disabled as a victim of a criminal offense stated that he was unable to receive sufficient compensation because he could not afford to file a civil suit. The criminal case was focused on retributive justice instead of restorative justice. However, in this particular instance, the criminal case failed in both retributive and restorative justice.

‘They were only sentenced for 7 years whereas I was permanently disabled for life. If I proceeded with the civil lawsuit, I would have had to spend way more than the 10 lakhs compensation I got from the High Court because of the delays in cases, and usually, you have to spend a lot of money for legal advice.’

An interviewee from Southern Province, Male, 43 years

3.10 Inequities in provision of administrative services

Persons with disabilities in all provinces reported that the services of the officials were welfare-based, and focused mainly on distributing aid. The government did not prioritise the design or implementation of programmes empowering persons

⁹⁴ For example, it takes about 10.5 years on average for a criminal case to be prosecuted at High Court according to the Sectoral Oversight Committee on Legal Affairs (anti-corruption) & Media, Recommendations Pertaining to the Expeditious and Efficient Administration of Criminal Justice (20 September 2017) 3.

⁹⁵ Government Information Centre, ‘Legal aid for disabled person: Disabled persons desk’ <<https://gic.gov.lk/gic/index.php/en/component/info/?id=1335&catid=30&task=info>> accessed 27 January 2023.

with disabilities to live with autonomy. In one province, when a local NGO commenced projects to train persons with disabilities on employable skills and tools for maintaining accounts, government officials joined to support them. But we did not come across instances where the government initiated such innovative approaches to empowering persons with disabilities at the local level.

The response of administrative officers to persons with disabilities had been cordial in instances where they were an acquaintance. But they were generally either indifferent or hostile. For example, one interviewee stated that she received an electronic sewing machine from the Divisional Secretariat. Since she was a member of the local women's society the officers of the Divisional Secretariat observed her need during their visits to her home and thereby, contacted the Women's Affairs Ministry to provide funds for a new sewing machine. In contrast, persons with severe disabilities, women with disabilities from female-headed households, and people from multiply marginalised communities such as Indian Tamils (from the estates), ex-combatants, and Muslims were ignored by the officials in service provision. Therefore, the services based on affinity excluded the most marginalised persons with disabilities and their families.

In many instances, government officials refused to take into account the specific requirements or concerns that the different persons with disabilities faced, thus denying services to the most marginalised persons with disabilities. For example, an interviewee from a female-headed household in the estates stated that she requested the disability allowance several times, but the Grama Niladari did not provide a response. This person-focus instead of service-focus resulted in the systemic violation of the rights of persons with disabilities.

3.11 Community engagement and lack of political engagement

I run a disabled welfare society to help people like me. I am the president of the association and the representative of disabled people at the district level. There are about 300 disabled members in our association; all of the members are fully or partially disabled. Some of them are disabled due to civil war, some are disabled by birth and some are disabled due to accidents. We have members of

many ethnic groups. We are providing various services such as economic and livelihood assistance.'

An interviewee from Eastern Province, Male, 61 years

The interviewees were members and leaders at community-level organisations. Seven interviewees worked in DPOs at the local level, two were members of welfare associations for persons with disabilities, and two stated specifically that they were advocating for the rights of persons with disabilities. One interviewee was also part of a local women's organisation.

But none of the interviewees were seeking office giving a voice for their concerns at the local, provincial, or national level decision-making bodies. Only one caregiver indicated that she would run in the local government election. Multiple barriers that persons with disabilities face in accessing public places, employment, and education as well as their socioeconomic status hindered them from engaging in politics.

Political parties had also made no targeted attempts at including persons with disabilities in their party ranks and campaigns. Persons with disabilities have not had the capacity to vote, engage in politics, and lobby through mobilisation due to systemic marginalisation. Therefore, the political parties and politicians continued to overlook the interests of persons with disabilities.

3.12 Attitudinal barriers

Persons with disabilities faced harmful stereotypes that treated them as weak dependants, burdens, victims, and anomalies. These various stereotypes undermined their autonomy, economic empowerment, and public participation. For example, an interviewee stated that she was not able to find employment because the employers believed that using the labour of a weak dependant such as her would undermine their reputation.

'Nobody wants to provide me a job because of my inability. The employers who I approach for work say we cannot offer work to a person like you, if I get work

done from you it is considered a sin for us. I have studied up to ordinary level (O/L), but nobody is ready to give me employment.'

An interviewee from Eastern Province, female, 42 years

Many interviewees could only engage in home-based self-employment because the state and society saw them as passive recipients of aid. This also led to seeing persons with disabilities as a burden to the family, the economy, and the state. Two interviewees stated that people complained when they were given priority in queues at the hospitals. Another interviewee with a bent leg stated that she did not use her artificial leg because she realised that the buses did not stop for her then. These examples showed how people viewed the presence of persons with disabilities in public as a burden.

Stereotyping persons with disabilities had created a societal expectation for them to behave as ideal victims: docile and hardworking. But persons with disabilities who were unable to meet their criteria were ostracised by society and the state. For example, an interviewee of old age with a psychosocial disability who behaved chaotically in the village and spoke in rude language was hated by the villagers. He did not receive any aid from the government as well.

Persons with disabilities were treated as anomalies and ostracised because of the lack of societal understanding, exposure, and empathy toward persons with disabilities. For example, a mother of a child with a psychosocial disability stated that people blamed the parents for not raising the child right without understanding the behaviours of disabled children. She stated that people were less aware of the disabilities that were not immediately visible, such as psychosocial disabilities. An interviewee also stated how she observed persons with disabilities and non-disabled persons sitting separately at events for persons with disabilities and that this saddened her. Another interviewee stated that his friends teased him for wearing glasses and that as a result of not wearing glasses, he gradually lost his eyesight completely. Such stigma towards disability as an anomaly undermined the dignity of persons with disabilities and marginalised them.

3.13 Women with disabilities and women caregivers for persons with disabilities

We came across several instances where women with disabilities face multiple discrimination based on their disability and gender. The main concern related to the insecurity that women with disabilities face in the context of high rates of gender-based violence and sexual harassment.⁹⁶ Caregiver mothers of women with disabilities indicated their constant anxiety towards their daughters.

'We do not have enough income to meet our basic requirements and I cannot go outside for work leaving my daughter alone. In emergency situations, I can leave her at my neighbour's house but if I ask their help on a regular basis, they will definitely refuse'

Caregiver mother of a person with a psychosocial disability, Eastern Province

Another mother raised her concern about who will take care of her physically disabled daughter once she passes away. Another interviewee from a household of four disabled sisters stated that they rarely leave their home. Even though they tried to engage in animal husbandry at home, they gave that up as well because pasturing outside their home was difficult for women. Other interviewees reported instances wherein women with disabilities faced sexual and physical abuse in public transport and in their homes.

We interviewed two women with disabilities who were also heads of their households. They struggled to take care of the dependents and provide for them. These women had no income and did not receive disability allowance. Their households were in abject poverty.

The majority of caregivers we spoke to were also women and they expressed difficulties in balancing their caregiving responsibilities with earning, which

⁹⁶ See, Department of Census and Statistics, Sri Lanka 'Women's Wellbeing Survey – 2019' (2020) 1 <https://reliefweb.int/sites/reliefweb.int/files/resources/srilanka_wws_2019_final_report.pdf> accessed 27 January 2023; UNFPA, 'Policy Brief: SEXUAL HARASSMENT ON PUBLIC BUSES AND TRAINS IN SRI LANKA (2015) 1 <https://srilanka.unfpa.org/sites/default/files/pub-pdf/FINAL%20POLICY%20BRIEF%20-%20ENGLISH_0.pdf> accessed 27 January 2023.

affected their family's economic status. Caregiver women spoke as if the norm was for the husband to abandon the family once a disabled child was born and seemed thankful where the husband remained. These observations made it clear that women took the primary responsibility for the disabled family member to be theirs.

4. COVID-19 RESPONSE AND AGGRAVATION OF VULNERABILITY EXPERIENCED BY PERSONS WITH DISABILITIES

4.1 Covid-19 as a ‘humanitarian emergency’

United Nations defines ‘humanitarian emergency’ as an event or a series of events that devastate or threaten the ‘health, safety, or wellbeing’ of a community or a group of people.⁹⁷ Article 11 of the CRPD requires the state parties to take ‘all necessary measures to ensure the protection and safety of persons with disability’ in such humanitarian emergencies. However, the interviewees stated that the Sri Lankan government did not consult the persons with disabilities in designing and implementing the pandemic response. Thus, the health and safety regulations, quarantine camps, lockdowns and curfews, and dissemination of information about these various measures did not take the interests of persons with disabilities into account at all.

4.2 Impact of health and safety regulations

4.2.1 Requirement to maintain one-meter to two-meter distance in public place

Interviewees with physical disabilities reported that people were hesitant to help them as a result of this requirement. The rationale of this rule is clear: to reduce the spread of the Covid-19 virus. Because many of Sri Lanka’s public spaces have not been modified to provide disability access people with disabilities cannot navigate them independently. Due to these barriers in the physical environment, this rule that restricted a third party from helping a person with a disability further restricted public participation for persons with disabilities.

‘Although the mentally-ill patients require a lot of care and love in caregiving, during this time such caregiving was also restricted because of social distancing and Covid stigma.’

A Medical practitioner, Sabaragamuwa Province

⁹⁷ United Nations definition on ‘humanitarian disaster’ see, <<https://www.ohchr.org/en/taxonomy/term/878#:~:text=A%20humanitarian%20emergency%20is%20an,usually%20over%20a%20wide%20area>> accessed 27 January 2023.

Persons from urban poor communities who lived in extreme congestion did not have the capacity to engage in effective social distancing. Their houses were too small and interactions with neighbours were inevitable. An interviewee stated that many persons including herself got tested positive for covid after the neighbouring community gathered to play cards during the lockdown period. She stated that busloads of people were sent to quarantine camps from high rises and her friend's disabled child died from covid. Therefore, she feared for her bedridden child's safety during this period because she knew their communities were extremely vulnerable.

4.2.2 Quarantine camps

While none of the persons with disabilities we interviewed directly experienced the quarantine camps that operated during the first wave in 2020, many stated their fear of being taken into these camps. They explained that there was no information that any quarantine camp disability access and therefore, they knew that they would not be able to survive in them without a caregiver. An unfamiliar physical environment manned by those who were unfamiliar with the needs of persons with disabilities was not conducive for them. The medical practitioner informed that persons with psychosocial disabilities faced discrimination in quarantine because the officials lacked the competence to communicate with such persons with disabilities.

Therefore, the possibility of being isolated in a quarantine camp itself caused grave stress for persons with disabilities.

'During the Corona period, neither I nor my family got any corona infection because my wife did not take anyone into the house. Our house was always locked. When outsiders come, they were kept outside the door and sent away. My wife had done these things as a precaution, fearing that I would become more ill and weaker.'

An interviewee from Northern Province, Male, 65 years

It was also a concern for their families because even if the caregivers are taken away, the disabled person would struggle to survive on their own at home. One interviewee mentioned that a son with a psychosocial disability committed suicide after the government took his sole caregiver mother away for quarantine.

Many persons with disabilities needed support in their homes or in accessing public spaces. For example, a person with a disability who lost his eyesight in old age stated that he was just learning to cope with his disability and thus needed help from family in his daily personal tasks. Several other persons with disabilities stated that they could function in their homes and other familiar places, like a place of religious worship that they frequent, independently, but that they needed support in other spaces. As a result, they and their families took extra precautions. Person with disabilities were particularly restricted to the home for the fear of coming to contact with the virus.

4.2.3 Hand sanitising/ hand washing stations

Persons with disabilities struggled to access the various types of hand sanitising and hand washing stations that were set up at the entrances to public places. Persons with physical disabilities could not operate the hand washing stations that required foot paddling and the height of these stations made them difficult to access from wheelchairs. Visually impaired persons struggled to figure out the different sanitising mechanisms available at different places.

'We had to use our legs to operate some of those installations and in these instances, it was hard to first see how they worked because I am visually impaired and I had to seek assistance since there were no special facilities that were given to the disabled.'

An Interviewee from Western Province, Female, 25 years

4.2.4 Requirements to use masks and use sanitisers

'Since my child was initially hesitant to wear the mask and the shield, he would remove it and throw it off. So, we had to buy extra masks and shields because of this.'

A caregiver mother of a child with a psychosocial disability, Western Province
Buying masks and sanitisers was an additional cost for persons with disabilities. Masks also inhibited the capacity of deaf persons to lip read, further inhibiting their capacity to comprehend what others were saying.

Moreover, if others were not following the mask mandate, then the persons with physical disabilities were at a higher risk because there is a higher chance of them coming to contact with the infected particles from their seated position. Visually impaired persons were at risk because they would not know if the bystanders were wearing masks or not.

4.2.5 Lockdowns and curfews

‘Since the buses were not operative, I could not travel to my hometown in Monaragala and it was almost like being trapped inside a house with no exercise or activity, thus mentally it was pressurising to me.’

An interviewee from Uva Province, Male, 33 years

Lockdowns made persons with disabilities complete prisoners of their homes. The situation was worse in households of multiple persons with disabilities. The lockdowns also detrimentally affected the persons with psychosocial disabilities whose conditions got worse due to the pressures of confinement and isolation.

‘Mental illnesses such as depression, OCD (because of having to adapt to new safety regulations), bipolar disorder (because of the challenges resulting from the scarcity of medicine) increased during this time.’

A Medical Practitioner, Sabaragamuwa Province

Children with disabilities showed weakened development due to the restrictions on attending school and interacting with friends. Persons with physical disabilities also stated that they felt depressed because none of their neighbours or friends could visit them during the lockdown. Interviewees articulated their loss of freedom as a mental strain, frustration, or just through disengaged stares. These responses raise concerns about the mental health impact of the lockdowns that was not explicitly

mentioned due to the overall lack of awareness, societal conditioning, and stigma attached to acknowledging, and voicing such concerns.

Interviewees from all provinces explained the difficulties of having to repeatedly explain to the police their reason for travel during the lockdown and the reason why they are with a third party in instances where only one person was allowed out. Some of the police officers did not treat them with respect even after hearing about their disabilities. One interviewee reported that the police obstructed their organisation from delivering essentials to the persons with disabilities in the area even though they had permission from the relevant local authority. Interviewees from North and East faced heightened scrutiny by the forces during similar situations due to the continued militarisation of these areas.

4.2.6 Access to information on health guidelines

Persons with disabilities we interviewed received information about lockdowns and curfews through the radio, television, neighbours, and announcements from religious institutions they were part of, through smartphones and social media. However, two interviewees who were in abject poverty stated that they did not have smartphones and therefore, their children also had no access to online education. Three other interviewees from different provinces also stated that they suffered from network coverage issues in accessing the internet and watching television news.

Interviewees further reported that deaf persons had issues accessing information through the television because breaking news was not interpreted in sign language and the curfew information was provided many times as breaking news. Interviewees who were deaf faced further barriers in comprehending the detailed health guidelines with their levels of literacy. For example, one interviewee related an instance of a person interpreting the social distancing guidelines applicable within the home as well. Thus, he maintained a distance from his family members, which led to the deterioration of his mental health. Similarly, persons with psychosocial disabilities also needed support from third parties in comprehending health guidelines and they were mistreated by the public authorities when they made mistakes due to the lack of awareness.

4.3 Access to essential goods and services

4.3.1 Food

‘Most of the disabled people in our area do not live near main roads, they live towards the middle of the rural areas. There were hardly any distribution services in those areas. Sometimes, they could not even find vegetables to eat. During the pandemic time, the prices of the products doubled and these economic challenges highly impacted the disabled community.’

An interviewee from North Western Province, Male, 63 years

‘Most of the time, we consumed rice porridge as our main meal. It was so difficult at that time, not only me many fishing people who lived near me also suffered from hunger without proper income.’

An interviewee from Eastern Province, Male, 43 years

The majority of persons with disabilities we interviewed reported unaffordability as the main hurdle they faced in accessing food. Several interviewees also hinted that they did not use gas or kerosene to cook anymore because they could not afford the costs. Many persons with disabilities did not have an income during the pandemic and had to rely on the disability allowance. While they received assistance from international organisations, local NGOs, and community organisations, these were not regular. Therefore, persons with disabilities and their families had to skip meals. One person with a disability stated that their family stopped buying milk even for their children since the pandemic. Persons with disabilities in coastal areas who received fish from the neighbour fishing communities stopped receiving them as the fishermen could not go fishing. Therefore, persons with disabilities mostly relied on homegrown items in their own homes and from neighbours.

‘Although the grocery delivery services were available, we could not buy the required groceries we would need because it was hard to afford them.’

An interviewee from Southern Province, Female, 67 years

In terms of accessing mobile deliveries, the interviewees reported situations where they did not reach rural areas and byroads. Persons with physical disabilities stated that they were not able to access delivery trucks because the drivers were unaware that a person with a disability was in the area. Deaf persons were also unable to access the trucks because they did not hear the announcements of their arrival. Therefore, persons with disabilities had to rely on their family members to access the food trucks even in the instances they had the financial means to afford to buy these goods.

Persons with disabilities also relied entirely on third parties in buying food and essentials from grocery shops due to the limited periods given to make purchases and the long queues. Two interviewees, one from an urban poor community and the other from a rural poor community, stated that they only bought essentials on credit from the nearby grocery shop and that they struggled when the shop was closed at length during lockdowns. They had to face the hostility of shop owners when they could not pay back on time.

4.3.2 Medicine and health services

Persons with disabilities faced difficulties in accessing pharmacies during the lockdowns, high costs of travel to hospitals, high costs of medicine and medical devices, unavailability of medicines, and stigmatisation of persons with disabilities at hospitals.

The interviewees stated that there were long queues in pharmacies and hospitals to buy medicine during the short intervals when the lockdown was lifted. Even though people were allowed to travel during the lockdowns for medical purposes, public transport was not available and private transport providers (such as three-wheelers) charged excessive amounts. As a result, persons with disabilities who were far from the hospital either stopped going to their regular clinic altogether, did the required tests at a closer clinic and sent the reports to the doctors through caregivers, or found a smaller hospital closer by. This lack of access to healthcare services and medicine detrimentally affected the persons with psychological disabilities who need regular visits to the clinics and care. Moreover, as therapy sessions were mainly available in Sinhala, those interviewees who spoke Tamil or English faced further barriers.

Many interviewees pointed out the costs of medicine and stated that they stopped buying medicine where possible due to unaffordability. However, in one area the government hospital posted their medicine to the regular clinic goers and visited the homes once the lockdowns lifted to check the patients and updated their records. However, the interviewees stated that now even these hospitals can issue medicine at the moment due to the drug shortage as a result of the economic crisis. People were required to buy medicine at private pharmacies at expensive rates. The price of medical devices such as catheters also started to hike during the pandemic period. Persons with disabilities who were in poverty struggled or were unable to afford the increasing costs of medicine and medical devices.

‘The hospitals rejected us (the disabled) and I personally experienced this rejection. Most of the public places rejected the disabled because of the fear that we would spread Covid and that we were not immune to the virus because of our disabled conditions.

An interviewee from North Western Province, Male, 63 years

Two interviewees from different provinces reported that they were not allowed to enter the hospital during the covid period or were specifically stigmatised due to their disability because persons with disabilities were seen as particularly susceptible to carrying and spreading the virus. However, other hospitals maintained Covid-19 support centres to serve persons with disabilities, especially persons with psychosocial disabilities. Therefore, the hospitals showed inconsistencies in awareness and service provision for persons with disabilities.

4.3.3 Assistive devices

The increasing costs of assistive devices that were essential for persons with disabilities affected their daily lives. For example, the cost of wheelchairs and the maintenance of the wheelchairs, and the costs of artificial legs affected persons with physical disabilities. Visually impaired persons also required mobile devices to access documents and information that increased in price. Deaf persons needed hearing aids. Bedridden persons with disabilities required a mixture of medical and assistive devices (such as diapers) that were costly. A caregiver mother of a child with a disability stated that she spent the entire disability allowance to buy diapers

and that she faced difficulties in finding diapers during the pandemic lockdowns. *'I am working with disabled people. I knew people who do not have diapers for disabled people and disabled children. This is really a pathetic situation of the country in terms of social welfare; the government is not looking for sustainable development projects for Sri Lankan people.'*

Caregiver brother of a person with psychosocial disability, Central Province

4.3.4 Sanitary items

Women with disabilities faced difficulties in accessing sanitary items during the pandemic because they were unavailable or unaffordable. Two interviewees from Western Province stated that they received sanitary items as part of the essential items distributed by NGOs and individuals. However, women from other provinces did not speak of this of their own volition. One interviewee stated that they used clothing when the sanitary items were unavailable or unaffordable, indicating that this was a personal need that they could neglect when the family needs became more pressing.

4.3.5 PCR tests

'When the ambulance/van comes to our houses for the testing they would ask us to get up and get into the van to do the test. But how can we do so on our own when we have a disability? Thus, we did not receive any empathy or support from the officials.'

An interviewee from Southern Province, Male, 38 years

Interviewees from two provinces indicated that the government officials conducted random PCRS during the first wave of Covid-19, but not thereafter. Persons with disabilities were unable to take the test in the subsequent waves due to the unavailability of PCR tests at affordable costs. They further stated that PCR tests were not available in the hospitals at the moment due to the medicine shortage. Therefore, anyone wanting a test has to pay and take it at a private hospital. This was a heightened risk for persons with disabilities who have underlying medical conditions.

4.3.6 Covid-19 vaccine

While interviewees from several provinces recorded priority for persons with disabilities, it was also evident that receiving priority was easier for persons whose disability was visible, such as persons with physical disabilities. The medical practitioner also concurred that the vaccine rollout was not organised at the initial stages and that the persons with psychosocial disabilities did not receive priority as persons with disabilities.

Some persons with disabilities reported that the Ministry of Health office in their area provided them with adequate information about the importance of taking the vaccine. Other persons with disabilities stated that they decided against taking the vaccine due to fears about side effects, the quality of the vaccines available in the country, and because of underlying health conditions. Two persons with disabilities stated that they knew of instances where disabilities worsened after the vaccines, so they refrained from taking the vaccine.

Persons with disabilities from the Western Province especially noted inequities in terms of the available vaccine types wherein Pfizer was not made available to the general public until much later. In these situations where they did not take the vaccine, they stated that they were extra careful and further limited travel out of their homes. Therefore, the choice not to take the vaccine also limited the physical for persons with disabilities.

4.3.7 Transport

‘There were no transport facilities for the disabled during the pandemic. Thus, we had to call 1990 (the ambulance service) when we required transport in case we wanted to go to a hospital.’

An interviewee from North Western Province, Male, 63 years

Persons with disabilities faced difficulties in finding transport to go to the hospital due to the halting of public transport amidst curfews and restrictions on inter-provincial travel. Interviewees from all provinces stated that they faced exorbitant three-wheeler costs and had to call an ambulance to go to the hospital. One interviewee reported an incident where a person got paralysed because the

ambulance could reach the patient on time because it was engaged in a personal errand of an official.

4.4. Loss of income due to pandemic response

'The pandemic time was a truly challenging time for the disabled community. Although I was self-employed and ran the ekel broom business, it was really hard to put the products into the stores during the pandemic period because there were no sales. As a result, our economic situation deteriorated a lot. It was a truly challenging period for most of us financially.'

An interviewee from North Central Province, male, 51 years

Self-employed and daily wage-earning persons with disabilities and their families were severely affected by the pandemic response. The self-earning persons with disabilities could not find the materials needed for their work and reach their usual market due to the lockdown. For example, fishermen did not go fishing and the person who was employed in making those materials lost her customers. The person with a disability who was sending her goods abroad suffered because of the restrictions on exports from foreign countries as a result of their Covid-19 response. The grocery shops run by interviewees were shut down because of the lack of access to goods and the dangers of coming to contact with the virus by associating with the customers. Another interviewee reported how her husband, who is also disabled, did not have his daily wage-earning labourer job for the entirety of the lockdown period. One interviewee stated that her mother did not so much as have the chance to earn a little income by selling their homegrown vegetables at the weekly fair.

'My father paints for a living. During the corona period, my father could not go outside to work. My brother was only paid very little. When the situation was too difficult, my mother borrowed money from the people in the neighborhood. Being the eldest child of my family, I feel very sad because I am of no use to my family.'

An interviewee from Northern Province, Male, 32 years

Only the persons with disabilities whose jobs allowed them to work online or received accommodations from their officers in duty rosters enjoyed a stable income during the pandemic.

‘One good thing is, I got my regular salary during that time, whereas many wage labourers and other people in our villages suffered without having an income.’

An interviewee from Northern Province, Female, 35 years

However, one interviewee explained how he worked as a frontline worker due to staff shortages in his workplace⁹⁸ and worked shifts without receiving any accommodations based on disability due to the fear of being ostracised as a free rider. These were all persons with disabilities who had studied up to the tertiary level or secondary level with extra training in IT skills with a job in a government or private institution.

4.5. Governmental social welfare schemes

Due to the loss of income, persons with disabilities and their families relied mainly on the disability allowance and Samurdhi. Additionally, the government also distributed Rs. 5,000 relief allowance -popularly known as the corona allowance- two times during the first wave. The Grama Niladaris in different areas followed different methods to distribute these allowances during the pandemic: some deposited the allowances to the bank accounts and others distributed the amount from gate to gate while taking the necessary health precautions. In other provinces, persons with disabilities or their caregivers had to travel to the Grama Niladari office when the curfew was lifted. However, several interviewees reported that there were delays in distributing these allowances, not receiving the amounts they signed that they received, and non-receipt of allowance for several months. Because they are almost entirely reliant on the allowance, delays meant that they would not be able to pay the credit at the grocery stores and that they had to skip meals.

⁹⁸ An institution providing healthcare.

4.6. Ethnic discrimination during the pandemic

Tamil and Muslim interviewees in militarised areas of the country faced heightened scrutiny in attempting to fulfil their basic needs during the pandemic. Muslim interviewees reported that they faced targeted discrimination due to islamophobia and ethnicity-based stereotypes that they lived in congested areas and thus were more prone to spreading the virus.

A Muslim interviewee reported how the neighbourhoods of Muslim communities were isolated at the very outset without sufficient notice. People within these neighbourhoods were not given any time to buy the essential items required to survive during the lockdown. The interviewee stated that even the Grama Niladari could not assist them because their areas were isolated. They had to ultimately plead with the military to lift the restrictions over their area, showing the military overreach over civilian matters.

The restrictions were only lifted on the condition of every person in the area facing a PCR test, but the interviewee stated that the officials made them wait for a long time and refused to provide any support to the wheelchair users. In another instance, when the officials conducted PCR tests in a vehicle, they demanded that the wheelchair users get into the vehicle on their own. The officials spoke to persons with disabilities in demeaning language.

4.7. Education during the pandemic

The sudden change to the online mode of education affected children with disabilities and children from families with persons with disabilities in several ways. While online education opened up new opportunities for persons with disabilities who had already attained a basic education, it came at the cost of worsening their disability. For example, an interviewee with partial visual impairment faced a risk of full visual impairment as a result of her excessive use of devices. Interviewee parents of children with psychosocial disabilities stated that they had to restrict online education for their children because of device addiction. Persons with disabilities who have not had a basic education, however, either struggled with accessing devices or have not been able to handle the devices at all. Parents who have disabilities stated that they were not able to provide their children with devices for online education due to abject poverty.

'My daughter also could not study well during the Corona time, she missed all the classes since online classes were carried out during the Corona, I don't have a smartphone therefore it was very difficult to carry out my daughter's education at that time. My daughter could score only 90 marks in the 5th standard scholarship exam and she could not pass the exam this year.'

An interviewee from Central Province, Female, 28 years

Persons with disabilities who were engaged in tertiary education also faced challenges.

'I had network coverage issues too that challenged my access to online academic activities. As a student who studied using the Braille method, shifting to an online system gave rise to many complications. When using the Braille system, the requirement for translation from the Braille system to the normal system arises. This was difficult during the lockdown. We had no access to campus and I did not have competent people around me to do the interpretation. Especially during exam time, this was an issue that we faced. I remember that afterward, we were given the ability to face some papers orally - a zoom meeting would be held and the questions would be asked so that I stated my answer instead of writing'

An interviewee from North Central Province, Female, 23 years

An interviewee who was attempting to apply for a tertiary educational programme during this period also stated the difficulties in contacting the government universities via phone. He further highlighted how he found the Learning Management System website to be complicated to navigate as a person with a visual impairment. He also mentioned that it was difficult for persons with visual impairments to follow the zoom lecture slides. The universities considered the needs of persons with disabilities in programmes where they were stereotypically expected to participate, such as courses on special needs education. But the same commitment to upholding equality through reasonable accommodation was not seen throughout the institution.

4.8. Privatisation of care of persons with disabilities

Private parties played a significant role in providing material and monetary assistance to persons with disabilities and families. While assistance from private parties was immensely helpful in sustaining the persons with disabilities, they were not regular and at times did not reach the most vulnerable. These limitations could have been minimised through effective interventions by state officials.

‘During the Corona, we could not do any business because of the lockdown and travel restrictions. My siblings gave some assistance to my mother who lives with me so; she shared that with our family. I also got assistance from some NGOs and our Mosque. Even though we got some assistance from various individuals and organisations, it was not enough for our family for one month.’

An interviewee from Eastern Province, Male, 43 years

Interviewees from all the provinces mentioned that they received dry rations, other essentials, and financial assistance from their extended families in the cities and foreign countries, neighbours, villagers, religious institutions, collectives of individuals such as university students and tuition class centres, and other well-wishers. However, in the days that they ran out of such assistance persons with disabilities and their families either resorted to rice porridge or skipped meals altogether when there was no aid. Interviewees also report instances where those in the rural areas and by roads and those who were not on the pre-prepared lists not receiving assistance.

4.9. Corruption in distributing Covid-19 relief

Persons with disabilities did not either receive Covid-19 relief or received lesser relief than was given due to corruption.

‘For example, if we sent a full hamper/’grocery pack’, by the time it received the receiver, the 1kg of sugar, the packets of biscuits would be removed.’

An interviewee from Southern Province, Male, 38 years

About five interviewees reported how receipt of Covid-19 relief was decided based on connections, to those who were known or related to local politicians, their supporters, or governmental officials. One interviewee mentioned that items were taken out from relief packages for persons with disabilities, sometimes with the active participation of government officials and police within the area. Another interviewee mentioned how persons with disabilities were misled and exploited on the promise that they would be provided with Covid-19 relief.

5. THE ROLE PLAYED BY THE INSTITUTIONAL STAKEHOLDERS

5.1 The state institutions

This section highlights the role of the central level institutions (executive led by the President and the cabinet of ministers, administrative bodies, Parliament, and the courts), central institutions deconcentrated to the local level (Divisional Secretariats and Grama Niladaris), and Provincial Councils and local authorities in upholding rights of persons with disabilities during the pandemic.

5.1.1 Institutions at the centre

The Sri Lankan government's Covid-19 response was designed and implemented from a privileged position that did not take into account the contextual nuances of the constituencies. Thereby, the pandemic response completely overlooked the circumstances of marginalised communities such as persons with disabilities. The government's neglect reinforced the negative stereotypes of persons with disabilities as a vulnerable group that would contribute to the spreading of the virus and a burden in the process of delivering a military-style eradication of the virus through survival of the fittest. Constitutional constraints that could hold the government to account politically, the members of the opposition in parliament, were not sufficiently mobilised to perform their role. The courts also were not proactive in holding the executive and administrative bodies of the government legally accountable.

The government could have consulted persons with disabilities in deciding their Covid-19 response, could have designed the health guidelines in a manner that accommodated the needs of persons with disabilities and could have communicated the health guidelines in a manner that was comprehensible to persons with disabilities. But the government did not attempt to do so. Many persons with disabilities engaging in self-employment and daily wage-earning employment lost their income as a result of the restrictions on movement. But the government did not adopt any policy to facilitate them in earning an income during the lockdowns. Sri Lankan government continued their overarching charity-based approach

towards persons with disabilities treating them as passive recipients of aid.⁹⁹ In addition to the general social welfare schemes provided by the central government, the government provided a relief aid of Rs. 5000/= (colloquially called the corona allowance) twice during the pandemic. But this amount was not at all sufficient for a community that lost their meagre incomes due to the government-imposed lockdowns that spanned across most of 2020 and 2021. Interviewees also reported instances where the disability allowance for low-income persons with disabilities and Samurdhi for low-income families were delayed, reduced, or not distributed for several months. In a context where the state has not taken steps to uphold the rights of persons with disabilities to participate equally in public and pursue economic empowerment, neglect in providing social welfare threatens the very survival of persons with disabilities. Many of our interviewees stated how they either skipped meals or ate porridge rice or rice and one curry when they did not have access to assistance.

The central government also engaged in distributing dry rations and essential items, but these have been one-time distributions that were limited to selected geographical areas. According to our interviews, the central government's distribution of dry rations has been limited to the distribution of food items in the North Central province one time, the distribution of food items once in the Western Province through the Disaster Management Authority, and the distribution of rice one time in the Southern Province in 2022. Whereas the foreign and local organisations and individuals distributed dry rations, essential items, and financial aid in all the provinces, the central government made no attempts to coordinate these efforts so that most needy persons with disabilities in all provinces would receive such aid. Furthermore, the government did not attempt to sequence private assistance so that persons with disabilities will continue to receive assistance throughout the pandemic response.

The central government also announced that priority will be given to persons with disabilities during vaccinating the general public. But our interviews revealed that this decision has not been consistently implemented across all provinces. Additionally, the governmental officials did not provide sufficient information to persons with disabilities on how the vaccine will affect their health conditions.

⁹⁹ Dinesha Samararatne, Karen Soldatic, Binendri Perera (n 41) 10-11.

5.1.2 The police

‘During the pandemic, disabled people were used for drug smuggling on the basis that they would not be checked by the police so often due to their disability. If it was a visually impaired person and if he was asked to exchange a parcel that contained drugs, well, he would not see what is inside the packet anyway. There was an incident where a deaf person was found with a parcel of drugs (which he had been entrusted to pass to another) and was beaten by the police. It was only after he was beaten that the police knew that the person could not speak.’

An interviewee from Southern Province, Male, 38 years

The police officers did not show awareness about persons with disabilities and their circumstances in enforcing the law. An interviewee reported instances where the officers misunderstood the circumstances of deaf persons because they did not know sign language. The interviewees from two provinces reported how police arbitrarily obstructed them from travelling to distribute assistance to persons with disabilities in the area. Another interviewee explained how it was difficult for persons with disabilities to file complaints with the police because that section was placed on the upper floors of an inaccessible building. Moreover, the police were lethargic in taking down complaints and taking action when persons with psychosocial disabilities were exploited over the pretext of giving Covid-19 packages. According to an interviewee, the police also took an active part in corruption in distributing assistance at times and used public property, an ambulance, for private use.

5.1.3 Central institutions at the local level

‘Most of the disabled, aged people could not go to clinics and get medicine during the pandemic. I believe that the MoH and the gramasevaka should have looked into this and should have taken the initiative to help the supply of medicine. But they didn’t do so and we later heard that the gramasevaka himself was scared to do so fearing he would contact Covid.’

An interviewee from Southern Province, Male, 38 years

The quality of services provided by the Divisional Secretariats and Grama Niladaris varied based on the individual professional commitment of the officials and the affinities they maintained with persons with disabilities. For example, a Muslim interviewee reported that the Grama Niladari of their area did not approach the people in the area throughout the pandemic due to the fear of contracting the virus. The government officials completely ignored providing services to people at the local level and delayed the distribution of the disability allowance. In contrast, an interviewee who maintained frequent and cordial relationships with government officials received better service. She stated that the Grama Niladari personally asked if they had the necessities during the pandemic and that the government officials called also phoned them. However, this experience was an exception because many other interviewees spoke of indifference and neglect.

Government officials at the local level had the potential to play a significant role in facilitating persons with disabilities to continue their home-based self-employment during the pandemic. But none of the interviewees spoke of the officials taking an approach towards empowering local communities before or during the pandemic. The government officials at the local level also had the capacity and information to coordinate foreign and private assistance distribution. Their coordination could have ensured that assistance reached the most vulnerable, most marginalised persons with disabilities and that such communities continued to receive aid. However, government officials failed to perform this task. As a result, while some houses received an excess of essential items that were then wasted, other households had to skip meals or eat sparingly. This led to the exponential rise of malnourishment in the country.

Their failure further resulted in cases where persons with disabilities were physically or sexually abused on the pretext of providing Covid-19 assistance. Additionally, interviewees also reported instances where the officials at the local level were active participants in corruption that occurred in the distribution of assistance, either by stealing items from aid packages or diverting aid packages for their own use or use of those in affinity with them.

5.1.4 Provincial Councils and local government authorities

Provincial Councils were elected throughout the pandemic period, so the persons with disabilities we interviewed did not refer to their role. But they spoke of the local government authorities: their role also being limited to a charity-based approach that prevailed across the central government institutions. For example, the interviewees mentioned that the Colombo Municipal Council provided aid for children with disabilities who engaged in special needs education and that the North Central Municipal Council provided a kidney allowance. These social welfare schemes were helpful for them during the pandemic. The Galle Municipal Council provided essential items to the homes of interviewees and the Jaffna Municipal Council coordinated aid received from foreign donor agencies. The medical practitioner reported that some Municipal Councils coordinated deliveries of medicines for persons with psychological disabilities. But the interviewees who lived within Urban Council and Pradeshiya Sabha limits did not report receiving similar assistance.

5.2 Non-governmental organisations (NGOs)

Systemic contributions of NGOs for persons with disabilities have been in providing them with avenues to engage with the community, collaborating to find resources for their basic needs, and organising programmes/training for their economic empowerment. In terms of facilitating community engagement, interviewees reported instances where the officers visited them at homes and engaged them with activities of their organisation which helped them come out of their homes. One interviewee reported that she found the outreach especially helpful when she was feeling frustrated from being isolated at home during the lockdowns. The organisation held zoom meetings during the pandemic.

An example of NGOs collaborating to find resources to provide for the basic needs of persons with disabilities was when an organisation wrote to the Housing Development Authority and got funds from a foreign donor to construct a house for three disabled siblings. Specifically, during the pandemic, the NGOs distributed dry rations and other necessities such as soap, shampoo, and women's sanitary items. Interviewees from all nine provinces mentioned that they received essentials from

the NGOs. The NGOs distributed goods to the homes of persons with disabilities, especially during the first wave of the pandemic. The persons with disabilities or their families were asked to pick up the essentials at the NGO offices during the second wave. This shows the dwindling capacities and resources of NGOs as the pandemic continued.

Whereas the NGOs that were operating locally from before the pandemic had the information on the neediest persons with disabilities, the NGOs and private organisations unfamiliar with the locality had limited outreach. One interviewee reported that such NGO assistance did not reach the neediest who were in the more rural areas and by roads. Another interviewee stated that such NGOs relied on a pre-prepared list that excluded the neediest persons with disabilities and families and that they refused to consider her when she made a request. These experiences showed the importance of collaborating with governmental officials in the locality and locally based NGOs in distributing aid.

5.3 Organisations of persons with disabilities (DPOs)

These organisations formed by persons with disabilities were registered with the divisional secretariats. These organisations were also confined in their focus to providing social welfare and facilitating community engagement for persons with disabilities in their area. The organisations lacked the expertise and the financial capacity to make long term advocacy for policy change even at the local level. Therefore, their response to the pandemic was also limited to the distribution of essential items. Several interviewees stated that they were the leaders of DPOs, thus initiating the distribution of dry rations and other essentials to persons with disabilities. However, these DPOs did not receive support from the local level officials and police consistently. For example, one interviewee reported that the police did not permit the distribution of aid to the members of his organisation who were in need even though they had a permission letter from the Municipal Council.

5.4. International organisations

While international and foreign organisations have provided material and monetary assistance to persons with disabilities, their lack of coordination resulted in the exclusion of the most vulnerable persons with disabilities. Interviewees from the Northern Province stated that they received dry rations and financial assistance from the World Food Programme and the World Health Organisation. Other interviewees from the Northern Province stated that they have not received this aid or that they were excluded. This could have been minimised through coordination among the state, NGOs, and DPOs at the grass root level.

6. RECOMMENDATIONS

This section details the urgent actions required to support persons with disabilities who are in dire conditions due to the government's pandemic response. Then the section also layout the systemic transformations required to uphold the rights of persons with disabilities in a holistic and meaningful manner. Finally, the areas for future research are highlighted.

6.1 Urgent actions

The main impact of Covid-19 on persons with disabilities was the collapse of their meagre economic status. A majority of persons with disabilities who were self-employed or daily wage earners lost their income as a result of the government's pandemic response. Their situation was worsened due to the onset of the economic crisis which skyrocketed the prices of most essential goods.

Therefore, the government needs to take urgent, immediate actions to ensure the survival of persons with disabilities and their families. The urgent actions should aim to achieve two purposes: firstly, to facilitate persons with disabilities to earn using their existing skills, and secondly, to provide social security for persons with disabilities who are unable to earn at the moment.

List of actions:

- For the Divisional Secretariats to identify all the persons with disabilities within their area and conduct a survey to assess their needs and their existing skills.
- For the President to make necessary budgetary allocations to assist persons with disabilities engaging in self-employment. This may include funds to commence self-employment with their existing skills or funds to restart the self-employment that collapsed due to the government's pandemic response.
- For the Ministry of Social Empowerment through its Social Services Officers to provide support services in finding the market for the products of persons with disabilities and in training persons with disabilities in business management to achieve profitability. The Ministry and its geographically deconcentrated officers can collaborate with local NGOs that are already engaged in such work.

- For the President to reassess the disability allowance taking into account the rising inflation. It is also important to specifically consider cases of multiple persons with disabilities in one family and dependents who rely on persons with disabilities and adjust the allowance accordingly.
- For the President to provide tax concessions for medical items and assistive devices needed by persons with disabilities.
- For the President and the Ministry of Social Empowerment with its deconcentrated officers to seek the support of international, regional, and local organisations and individuals who are interested in assisting persons with disabilities. Government officials should take the lead in facilitating and coordinating such support so that such assistance reaches the most vulnerable persons with disabilities in the proper sequence.
- For the Parliamentary Sectoral Oversight Committee on Health, Human Welfare, and Social Empowerment together with the Sectoral Oversight Committee on Legal Affairs (anti-corruption) and Media to monitor the process.

6.2 Actions for systemic transformation

Persons with disabilities are subject to continuous systemic discrimination and exclusion in Sri Lanka. It is due to this pre-existing marginalisation that the pandemic response disproportionately affected persons with disabilities. Therefore, the State has an obligation to take action to eliminate the systemic discrimination of persons with disabilities.

6.2.1 Constitutional

- Disability should be expressly recognised as a ground of non-discrimination in Article 12 (2) of the Constitution.
- Recognition of the rights of persons with disabilities expressly in the fundamental rights chapter (Chapter III of the Constitution).

6.2.2 Legislative

- For the parliament to enact enabling legislation incorporating rights enshrined in the CRPD.
- Ensure the effective participation of persons with disabilities, caregivers, organisations, advocates, and researchers in the process of enacting the enabling legislation.
- Ensure that youth with disabilities, women with disabilities, and persons with a diverse range of disabilities are included in the process of enacting the enabling legislation.
- Ensure that the enabling legislation recognises a multi-ministerial, multi-sectoral approach toward implementing the legislation.
- For the parliament and its Oversight Committees to regularly monitor the implementation of the legislation on the rights of persons with disabilities and coordinate with the Human Rights Commission and Ombudsman in this process.
- Introduce digital voting for persons with visual impairments.
- To enhance the regulation of political parties also with the aim of enhancing political representation and participation of persons with disabilities.

6.2.3 Executive

- For the President and the Cabinet of Ministers to recognise ‘rights of persons with disabilities’ and ‘disability inclusive development’¹⁰⁰ as a subject with the President or the Prime Minister’s office and mainstream the subject of disability through a right-based approach in coordinating the actions of the Ministries.
- Update the National Action Plan on Disability reiterating the significance of a multi-ministerial, multi-sectoral approach to implementing the rights of persons with disabilities.

¹⁰⁰ ‘Disability will be included disability in mainstream planning, training, implementation and monitoring of development strategies, actions, programmes and activities,’ in Padmani Mendis, Binendri Perera (n 35) 18.

6.2.4 Financial

- For the President and the Cabinet of Ministers to propose adequate budgets to uphold the rights of persons with disabilities.

6.2.5 Administrative

- Department of Census and Statistics to conduct a special census of persons with disabilities following internationally accepted classifications of persons with disabilities. This census should also include gender, ethnicity, language, and geography based sub-categories.
- Department of Registration of Persons to issue a special identity card for persons with disabilities based on the information provided by the Department of Census and Statistics.¹⁰¹ (Currently, the Department of Social Services issues an identity card to deaf persons. But this identity card reinforces persons with disabilities to be recipients of social welfare as opposed to recognising disability as a part of human diversity¹⁰²).
- The Ministry of Technology to digitalise the records of persons with disabilities so that the officials can access their details for official purposes. This data should be adequately protected through data protection legislation.
- Authorities providing vocational training to collaborate with the vocational centres within the purview of the Social Services Department to expand the number of such centres available within Sri Lanka, diversify the range of vocational training available, and link the trainees with potential employers and the market (ranging from government to private, local to international).
- Ministries of Industries and Trade to launch programmes for economic empowerment of persons with disabilities in collaboration with the Ministry of Social Empowerment.

¹⁰¹ Interviewees informed us of how they had to prove their disability again and again, for example, by producing medical certificates when they had to sit for an examination. They faced further challenges in convincing the public officials and police of their disability. Persons whose disabilities were not visible faced heightened challenges in these instances. They suggested an Identity Card as a solution for these difficulties.

¹⁰² Department of Social Services, 'Issuing Identity Card for the Hearing Impaired' <https://www.socialservices.gov.lk/web/index.php?option=com_content&view=article&id=26&Itemid=135&lang=en> accessed 23 January 2023.

- Ministry of Education to adopt inclusivity and rights education as part of early childhood education, to ensure that children with disabilities are in the classroom with their non-disabled peers and provide support to them through the Special Units and to monitor whether schools facilitate the trained teachers on special education in teaching the children with disabilities.
- University Grants Commission to provide access to special intake based on disability and not based on whether the mode of exam is braille or not, to expand the special intake, to establish and expand the Support Centres for Persons with disabilities in all universities, and to encourage private universities to provide scholarships for students with disabilities.
- Urban Development Authority and Rural Development Departments at the Provincial level to monitor the status of accessibility to public places within their purview and the quality of accessibility modifications to public places. The Parliament should oversee this process.
- Ministry of Health to establish a mechanism to receive complaints of the negligence of healthcare providers, both personnel and institutions.
- Ministry of Health to provide training to healthcare providers on engaging with and providing requisite information to patients with diverse disabilities, socioeconomic status, and education levels.
- Ministry of Health to mainstream programmes on mental healthcare.
- Ministry of Women's Affairs to specifically include women with disabilities in their programmes.
- Training the public officials (including the police) on engaging with persons with disabilities in a manner that uphold their dignity and rights as part of their initial training.
- Conducting annual continued professional development programmes for public officials on service delivery in a manner that upholds rights of persons with disabilities.
- Ministry of Transport and Highways to provide staff training on upholding the rights of persons with disabilities in their service provision.

- Ministry of Public Administration to maintain a mechanism (via telephone) to receive complaints of persons with disabilities who are aggrieved due to actions or inactions of a public official.
- Ministry of Mass Media to ensure that state media provides all news in a manner accessible to all persons with disabilities and to regulate private media to ensure the rights of persons with disabilities.
- The Legal Aid Commission to expand its service provision in provinces to take into account the special circumstances of persons with disabilities and to uphold their rights.
- The Attorney General's Department to take into account the special circumstances of persons with disabilities in assisting the courts.
- The Judges' Training Institutions to conduct research and provide the judges with training on engaging with persons with disabilities in the judicial process.
- Office of Reparations to implement their Reparations Policies and Guidelines 2021 and provide urgent reparations for war-affected persons with disabilities.
- Department of Social Services to continue with the provision of welfare to low-income persons with disabilities and persons with severe disabilities who are unable to earn a living.
- National Council of Persons with Disabilities and National Secretariat of Persons with Disabilities to facilitate consultations with persons with disabilities representing different provinces, ethnicities, genders, ages and socioeconomic status in designing and implementing ongoing and future crisis responses.¹⁰³

6.2.6 Human Rights Commission and Ombudsman

- To monitor the implementation of administrative actions to uphold the rights of persons with disabilities.

¹⁰³ An interviewee suggested to appoint a special consultative committee to accommodate the needs of persons with disabilities into account in designing and implementing future governmental responses to emergencies.

6.2.7 Commission to Investigate Allegations of Bribery or Corruption

- To monitor the corruption of public officials in the provision of assistance for persons with disabilities.
- To expand their provincial mandate and provide required assistance and priority for persons with disabilities in making complaints.

6.2.8 Provincial Councils and local government authorities

- To mainstream the rights of persons with disabilities at their respective levels.

6.3 Themes for future research

- We were only able to interview one person from the Indian Tamil community and two persons from urban poor communities living in *wattes* and high rises. Whereas these interviews provided insights into the distinct kinds of marginalisation they face, further research is required to appreciate the full extent of the vulnerability.

CONTRIBUTORS

Interviewers

- Ms. Theshani Weligamage
- Ms. Anuja Moses
- Ms. Binendri Perera

Interview facilitators

- Ms. Avanka Fernando - Faculty of Arts, University of Colombo
- Mr. Chamara Prasanna Silva – Deaf Link
- Coordinators of organisations for the disabled
- Development Officer - Jaffna
- Mr. Geeth Kumara – Navajeevana
- Grama Niladhari officer - Kinniya
- Ms. Krystle Reid – Enable Lanka Foundation
- Ms. Krishanthi - Field officer, Navajeevana
- Ms. Sandhya – Field Officer, Navajeevana
- Midwife – Northern Province
- Mr. Muditha Wagasinghearachchi - Navajeevana
- Dr. Nayanalie Daasanayake - RCCI Rehabilitation Centre for The Communication Impaired
- Ms. Pushpa Galhena – Community mobiliser and leader, Western Province
- Ms. M. F. Rafeeka - Central Province
- Secretary - Disability Welfare Society, Northern Province
- Senior Mobiliser – Viluthu Organization
- Mr. Sunil Nanayakkara – Consumer Action Network Mental Health Lanka

Interview coordination - organisations

- Consumer Action Network Mental Health Lanka
- Deaf Link
- Disability Welfare Society - Northern Province
- Enable Lanka Foundation – Hokandara

- Navajeevana Rehabilitation Centre – Tangalle
- RCCI Rehabilitation Centre for The Communication Impaired – Colombo 5
- Viluthu Organisation - Jaffna
- Welfare Association for Diverse Ability- Trincomalee

Deepening Vulnerability: COVID -19 and Disability

Binendri Perera

This report is based on a case study that analyses the experiences of thirty two persons with disabilities. The research team chose the interviewees to reflect various ethno religious groups of Sri Lanka, genders, and economic and social conditions from all nine provinces. The report explores how persons with disabilities were affected by the Sri Lankan government's response to the COVID-19 pandemic. The narratives of the interviewees reveal that persons with disabilities face systemic discrimination in every aspect of their daily lives, and such marginalization was drastically exacerbated by the pandemic response. The poverty that persons with disabilities and their families suffered worsened as a result of the recurrent crises. The report concludes that the state must initiate urgent and long-term actions to uphold the rights of persons with disabilities.

Binendri Perera is a D.Phil. candidate in law at the University of Oxford.



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