

IMPACT OF COVID-19 ON PERSONS WITH DISABILITY IN MALDIVES

Results of quantitative and qualitative research findings

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Introduction

In March 2020 the World Health Organization (WHO) declared the outbreak of COVID-19 as a pandemic. People with disability may also be disproportionately impacted by the pandemic due to limited access to basic services which they rely on.

This report focus an analysis on the impact of COVID-19 on persons with disabilities (PWDs) through the data collected in the first round of self-enumerated online survey on Socio-Economic aspects of Covid-19 in the Maldives (Round 1 – May 2020) and in-depth interviews with key informants involved in the Covid-19 response directly or indirectly. The research was approved by the National Health Research Council (NHRC/2020/006).

Disability has been measured based on the Washington Group Short Set on Disability (WG-SS). The questions used the ICF as a conceptual framework. The WG recommended cut-off has been used to define the population of persons with disabilities as 'those with at least one domain that is coded as a lot of difficulty or cannot do it at all.'

Survey Findings

The focus of this report is on the concerns of PWDs with reference to COVID-19 and providing social support and access to health. Supplementary information is provided on their economic empowerment, with the effect of COVID-19 on their income.

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Disability prevalence

This is much higher than what was found in the recent studies; according to Maldives Household Income and Expenditure Survey (HIES) 2019, the prevalence of disability is at a standard 8% (NBS, 2020). This difference could be a result of voluntary participation in the study that have introduce some amount of sampling bias.

Table 1: Prevalence and mean age	Male	Female
Percent of population with disability	13.4%	14.9%
Mean age among persons with disability	34	30

Disability is higher among women than men and the average age of a person with disability captured in the survey is 32 years.

Concern over care/support during & after pandemic

Data on different concerns with regard to spread and containment of COVID-19 measures was collected in the survey.

Since the very beginning, the government has taken measures to include the most vulnerable population in their communication measures and to follow WHO guidelines. This include having sign interpretation at media briefing and other COVID-19 public awareness messages for PWDs. Effective communication has reached those staying at home with limited functionality. Media has played a pivotal role in educating the masses on the COVID-19 prevention.

Due to shutdown of business and daily life, many PWDs were left to render for themselves. Lockdown and maintaining physical contact and adherence to them becomes a challenge due to the nature of their disability. Caretakers, health personnel could not make home visits to provide the necessary service for the most vulnerable of this group. As a result, PWDs are placed in a real bind when it comes taking care of themselves and daily activities of life. Due to the nature of their limitation, this COVID-19 adds additional dimension of concern over care during and after crisis. Among respondents with disability, 66% noted concern with the ability to cooperate and support one another during the crisis. Respondents without disability noted most concern, as they are most likely to face the overburden of taking care of persons with disability, the elderly and children.

Table 2: Concern over care	Without disability	With disability
during the crisis	74%	66%
after the crisis	72%	63%

Similar concern is also noted among persons with and without disability over care after the crisis.



Not all PWDs are at high risk of becoming infected with COVID-19. Some people with disability are at a higher risk due to the nature of their underlying medical conditions. However, health related issues should not be undermined at this moment of time when the health personnel are getting overburdened with the increasing cases of hospitalization.

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The finding from the survey shows that concern over health issues is more compound among the PWDs. During these unprecedented times, it is expected to trigger stress, mental health conditions even among normal people. The findings show that stress resulting from confinement is quite high (at 62%) among PWDs. Confinement of living in small spaces, social distancing and having to rely on themselves has taken a toll on this vulnerable group.

At times like this, access to health service is crucial for PWDs. The impact on mental health is much more among PWDs, perhaps a reflection of their vulnerability. Otherer studies have found higher level of stress during lockdown, particularly among those with intellectual disabilities (Courtenay & Perera, 2020). Literature shows the beneficial role of telehealth during disasters and public health crisis (Lurie & Carr, 2018).

Table 3: Health concerns	Without disability	With disability
About stigma	33%	34%
Over stress from confinement	44%	62%
Health of household member	70%	71%
Health of vulnerable population	83%	82%
Health of PWDs	84%	80%
Overloading the health system	89%	90%

Our study has shown that more people with disability have accessed health services during this pandemic than those without disability. Majority has gone for online consultation proving that this is a viable mode of delivery health services to the most vulnerable population and saves time taken by them to get ready and travel to seek medical consultation. It Is important to continue the good practices introduced during this pandemic to better serve PWDs and other vulnerable populations.

Concern over health- related issues

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However, another important issue to address at this point would be those that did not access health service when needed. This might have its consequences on their health ultimately and might add to prolonging ill health if not treated properly. Households having PWDs should ensure their health needs are met even during this pandemic.

Table 4: Access to health services	Without disability	With disability
Went to a health facility	10%	11%
Used online health services	19%	24%
Did not access health service when needed	5%	8%
Did not have to use a health service	63%	54%
Other	2%	2%



Income and job security

The integration of PWDs into work is adversely affected by their lack of functionality. They are more likely to be unemployed and outside labour force.

COVID-19 has put forth uncertainty in our livelihood. Whether we will have job security, income, donations and transfers same as before is questionable. Our findings showed that majority of the population with and without disability are engaged in a job. About 7% of the persons with disability owned a business.

Table 5: Main source of income before COVID	Without disability	With disability
Employed at a job	64%	63%
Own business	11%	7%
Family business	3%	2%
Rental income	4%	3%
Pension	1%	1%
Donations	1%	1%
No income	13%	18%
Other	4%	4%



The results showed comforting news as more than half of the PWDs and non-PWDs report on job security even during this pandemic. However, 6% of the PWDs had lost their job consistent with that among those without disabilities. However, it is noteworthy that 5% of PWDs were not in a job.

Table 6: Status of job due to COVID	Without disability	With disability
Lost job	5%	6%
On reduced salary	30%	25%
On no pay leave	5%	5%
May loose the job	8%	7%
Job secure	51%	52%
Not in job	1%	5%

Furthermore, 44% of the PWDs have stated that COVID-19 has had a huge impact on their financial obligations; in having to pay for their utility bills, paying rent, etc. Other country studies have shown that disability workforce is overlooked in pandemic response (Cortis & van Toorn, G. 2020).

KEY INFORMANT INTERVIEWS

Three key informants were interviewed on this aspect: one from a government institution and one from a civil society organisation working with PWDs and one from the National Emergency Operations Centre (NEOC). Mental health is not covered in this section as it is addressed separately.

Planning & Coordination

Participants felt that the response and relevant government institutions were not prepared to address to the needs of the PWDs. Both government and CSOs working with PWDs were not part of the NEOC. While they got the opportunity to take part in some of the meetings for response, the communications and coordination were not streamlined and required outputs were not realized.

Multi-agency coordination (MAC) was instituted as function within the planning cluster at NEOC. The operations however focused on business continuity of selected essential services like utilities, waste management, transport, and communication. It appears the coordination with CSOs was overlooked in the MAC at the NEOC. The need to ensure inclusivity of vulnerable populations in pandemic response planning have been raised by a scholars during the COVID19 response across the globe (Armitage & Nellums, 2020) "We had regular meetings with multiple agencies and worked with them for business continuity, CSOs was not included in the MAC. We are not sure which cluster coordinated with NGOs.. may be admin and HR cluster was liaising with them as they had the function to mobilize volunteers" (NEOC)

"But I think we were lacking on what we needed to do. Even when Mental Health and Psychosocial (MHPSS) cluster was being formed, they were trying to figure out the challenges they were coming up against and formed subgroups based on those. I think when things like this was done the communication was not good, maybe not to the best form of it. Because we were honestly very lost when we were trying to form the cluster. We discussed in the meetings things to do, but in my opinion, it was not very constructive." (CSO) **Planning and Coordination**

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The needs of the PWDs cut across many functions of the pandemic response and it was observed that coordination with government counterparts on the special needs of PWDs were difficult. The absence of a specific number set up to coordinate the response with CSOs on social service made things worse and often CSOs had to rely on personal networks to get things moving. However, CSOs were able to work well together; ARC and Care Society partnered to provide essential items to the PWDs during the lockdown.

"Community get in touch with us or the relevant ministry for needs of PWDs, particularly children. For example, when PWDs are in need of medication, we try to coordinate with the government counterpart, but we they don't get back to us or don't pick up the phone... and we have no answer to the parents when they call us to follow-up." (CSO) The policy arrangements for coordination with CSOs was noted to be ineffective for the disability sector, since the CSO liaison mandate was with Ministry of Youth Sports and Community Empowerment (MoYSCE). This is particularly so as the CSOs in this area is very specialised and work regarding PWDs falls with Ministry of Gender, Family and Social Services (MoGFSS), the coordination on the ground had to be with MoFGSS. There was no organized networking of the NEOC response with MoFGSS and CSOs, which if instituted could have benefited the reach and support to PWDs, since the CSOS have grassroot level information on the PWDs and their specific needs. Reaching out to the CSOs and overall coordination with CSOs during the lockdown was not well managed.

"People call us more than the ministry when they face this type of difficulty, even getting food. Even with all this happening, CSOs even in the islands can give lot of information, numbers of PWDs. So there needs to be a mechanism where CSOs can complement the work of the government institutions that work on the specific issues. I feel that strengthening such a network is very important." (CSO) Useft behind

The COVID-19 response lacked inclusivity in its response and recovery planning, which was one of the reasons for poor coordination with government institutions and CSOs working with PWDs. Other countries have also noted that protection of PWDs were overlooked including those of income loss (Pineda & Corburn, 2020).

"we advocate and promote the need to strengthen the network for PWDs. We are here to work with them. Input form people working at the grassroot will be very helpful. We saw such gaps a lot. When we talk of inclusivity, how much of inclusivity was there in this. For example, if we look at this (Covid19 EOC) operations, did we have that inclusivity plan for PWDs? Such questions arise" (CSO)

Risk communication attempted to ensure inclusivity by providing sign language interpretation at the press conferences. However, concern was expressed that, in risk communications and awareness messaging the carerers and parents of PWDs, particularly children with disabilities (CWDs) were not targeted, and the whole spectrum of disabilities were not addressed. This is not confined to the Maldives, and concerns have been expressed in other countries that the framing, measures, and policies implemented have fallen well short of what is required for inclusivity of PWDs (Goggin & Ellis, 2020). The design of communication materials and graphics did not consider access to the information by those who are blind while current technology provides the opportunity to do so. Although guidelines were prepared by the CSOs for risk communication focussed on caregivers of PWDs, it was not used.

"We tried to ensure PWDs also receive the information. We included sign language in all the press briefing. We had volunteers doing this at all press briefings" (NEOC)

"We developed and shared with NEOC the guideline how to provide information to PWDS and parent of CWDs, story line on how to prepare CWDs for hand washing and hygiene, preparing them for quarantine and isolation, but we don't know what happened" (CSO)

Working outside the response

Social protection sector and CSOs largely worked outside the NEOC structure, often supported by UN partners. Disability sector CSOs noted that they conducted several programmes, providing psychosocial support to PWDs and guidance to manage CWDs. They were able to provide outreach support to PWDs/CWDs not only in Male' but in the Atolls during the lockdown. The work of the CSOs at the periphery of the pandemic response was critical to ensure PWDs continue to receive the support required to ensure their wellbeing, and self-determination, especially when they are put in situations where their regular caregivers are quarantined, and unable to continue providing support (Pineda & Corburn, 2020).

"We directly worked with parents, in Male' and in Naifaru. With support of UNICEF we provided items necessary for their therapy, things like clay (play dough)." (CSO)

The high dependence of the families on healthcare providers and therapy service providers was a major concern at the time of lock down. Movement restriction and scaling done of the services meant no access to disability services. Access to therapy for PWDs were provide solely by the CSOs through telephone and online consultations. This however, proved to be extremely challenging since the families and carerers had not been empowered to care for PWDs themselves.

"The greatest concern was the minimal involvement of parents and carer in the therapy of PWDs, there is a dependency on the therapist, doctors or teachers regarding all aspects of their disability.. we have shown them (parents) that they can do this... and this is most productive in a way. Not to depend on a third party to do this. I do hope that they also hold onto this learning" (CSO)



Business continuity

CSOs developed basic contingency plans, to provide support and therapy to their clients through online modalities, which had proved quite effective. They are incorporating such blended modes of support into their regular programmes going forward. It was noted that provision on therapy through online modalities meant the therapy had to be delivered through the parents, which was a huge challenge. However, this led to empowerment of several parents and gave them confidence in managing their CWDs. The main challenge was the loss of funding for the CSOs working in this sector, that were dependent on donations. It was noted that even when MoYSCE worked on recovery, much of it was focussed on sports sector CSOs rather than issue specific CSOs.

"We saw MoYSCE work with sports CSOs and assuring funding, for example, working to assure national players salary. With all the things that has happened we do not see focus to sustain issue specific CSOs, did not work to reach out to the other CSO. Our thinking is to minimize the in-person services and continue online technology-based services for the PWDs. Then we will try to mobilize funding for projects from international donors." (CSO)

Conclusion



The survey findings did not show marked differences in the general socioeconomic experiences of PWDs compared to the general population. However, PWDs used more health care, and more PWDS experienced stress from the lockdown measures, indicating the higher needs to this group that were not adequately addressed. Furthermore, economic parameter showed that more PWDs did not have any income compared to the general population.

The qualitative findings indicated that issues around protection of PWDs were largely left behind in the COVID-19 response. Planning and coordination, working outside of the national response, exclusion and business continuity of service providers are the key themes observed.

Planning did not include a specific focus on PWDs and attending to their specific circumstances, except communications to some extent has included reaching the messages to the deaf. Coordination was poor and fragmented with no mechanism for liaison with NEOC, in fact there was no social protection cluster embedded in the NEOC structure. Operational processes did not have specific protocols for addressing the range of needs of the PWDs, particularly CWDs that resulted in ad hoc interventions for providing support when they or their caregivers had to be quarantined and isolated. Business continuity of support agencies was hard hit, requiring them to find innovative modalities for providing support and therapy for PWDs, limiting their reach to PWDs. Support from government institutions for recovery has not reached the CSOs of the disability sector.

Establishing a social protection cluster at NEOC and strengthening the networking with CSOs with the relevant government institution that has the issue specific mandate, is critical to ensure inclusivity of PWDs and their needs in future pandemic response. Furthermore, the opportunity to increase involvement of families in the care of the PWDs particularly CWDs, and reduce dependence on health care providers and therapists, was a positive learning. This empower the families and PWDs needs to be sustained to ensure they are not left behind during such emergencies in the future.

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