

Research & Studies
From project

Prevention against Emerging Infectious Diseases: An opportunity for Inclusive Health

Understanding the behavioural and social drivers (BeSD) of COVID-19 vaccination among persons with disabilities in Internally Displaced camps in Somalia/Somaliland

Inclusive Global Health Division & Somalia programme
July 2023

RS | FP | 44



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A Humanity & Inclusion publication

Global Inclusive Health Division

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Photo credits

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Disclosures

This study was funded by the Universal Health Coverage and Life Course (UHL) division of the Immunization, Vaccines and Biologicals (IVB) department of the World Health Organization, Geneva. Humanity & Inclusion also carried out a Risk Communication and Community Engagement (RCCE) project, contributing to the inquiry phase described here, to foster the right to health as well as access to COVID-19 vaccination in Somalia/Somaliland, funded by Center for Disaster Philanthropy.

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Executive summary

Context

Handicap International - Humanity & Inclusion (HI) started its Somalia/Somaliland intervention in 1992 by setting up a rehabilitation centre in Hargeisa. HI's strategy in Somalia/Somaliland aims to advocate for the rights of persons with disabilities and to promote their inclusion and participation. Thus, HI's programmes in the country focus on promoting inclusive humanitarian action, protection against abuse and violence, rehabilitation, Mental Health and Psychosocial Support (MHPSS), and Inclusive Health.

According to the World Health Organization (WHO), in April 2023, Somalia counted 27,334 confirmed COVID-19 cases since January 2020 and 1,361 deaths. The country has managed to fully vaccinate 30% of its population against SARS-CoV2. After reacting to the COVID-19 health emergency, HI planned to carry out a Risk Communication and Community Engagement (RCCE) programme to ensure the right to health information and prevention for the most vulnerable groups, like persons with disabilities living in Internally Displaced (IDP) camps.

General and specific objectives

In close collaboration with WHO, HI adapted and piloted WHO's behavioural and social drivers (BeSD) of vaccination tools¹ to understand and analyse the perception of COVID-19 vaccines as well as the barriers and drivers of immunisation among persons with disabilities in a humanitarian setting. The overall goal of this study was to capture the unique drivers of health prevention for Persons with disabilities in Somalia/Somaliland to support evidence-based disability-inclusive prevention (like RCCE programmes) and strengthen advocacy for inclusive health information and services.

Specific objectives:

- To identify key drivers and specific barriers to COVID-19 vaccination and health prevention practices among persons with disabilities in IDP camps in Somalia/Somaliland;
- To pilot the use of the BeSD tools among persons with diverse types of disabilities to propose concrete recommendations for their inclusive use worldwide.

¹ WHO. Behavioural and social drivers of vaccination: [Tools and practical guidance for achieving high uptake](#) [Internet]. WHO website. Geneva: WHO; 2022 [cited 2023 Aug 3].

Method

This study followed a mixed method using the BeSD tools for quantitative (22 questions) and qualitative data collection. On the one hand, a trained HI team surveyed 277 persons with disabilities. The survey was designed to generate a 95% confidence level and a 5% margin of error for each population group in the target locations. On the other hand, another trained HI team interviewed 30 adults with disabilities and 30 health workers. Both parts of the study used disaggregated data analysis by age, gender, and disability. Disability status was self-reported using the short set of the Washington Group Questions (WGQs), considering that many respondents (86%) reported two or more disabilities. This study did not have a control group and does not compare the situation of persons with disabilities with the overall population's. The analysis is framed within the BeSD theory of change, which clusters drivers and barriers around four pillars: Thinking and Feeling; Social Processes; Motivation; and Practical Issues.

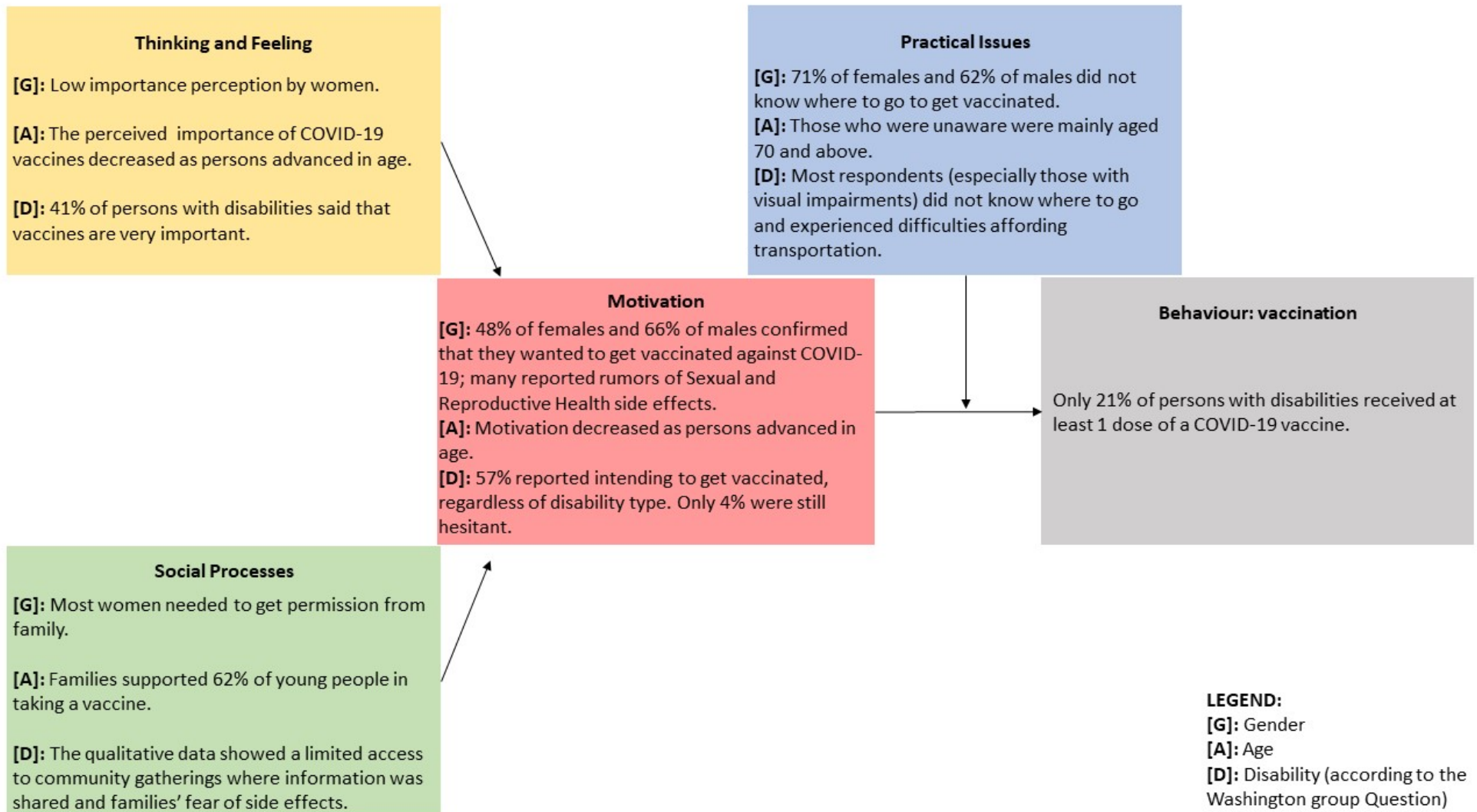


Figure 1: The BeSD framework, with the four clusters of drivers of vaccination behaviours

Findings

QUANTITATIVE ANALYSIS:

- **THINKING AND FEELING**
 - **[A]** We found a statistically significant association between older age and a negative perception of the importance of COVID-19 vaccination.
 - **[G]** The results also showed that the perception of the importance of the vaccines was lower among women, but not statistically associated with the respondents' gender.
 - **[D]** There was a statistically significant association between the perception of the importance of COVID-19 vaccines and hearing or self-care disabilities.
- **MOTIVATION**
 - **[A]** The results demonstrated that as persons advanced in age, their motivation to receive a COVID-19 vaccine decreased.
 - **[G]** There was a statistically significant association between the motivation to get vaccinated and gender.
 - **[D]** There was no statistically significant association between the motivation to get vaccinated and disability type.
- **SOCIAL PROCESSES**
 - **[A]** Younger persons were more likely to think that close family and friends wanted them to get vaccinated against COVID-19.
 - **[G]** According to the data and Pearson's chi-square test, gender was not associated with this perception.
 - **[D]** There was a statistically significant association between this perception of family norms and visual disability, but not other disability types.
- **PRACTICAL ISSUES**
 - **Information**
 - **[A]** Younger persons were more likely to know where to go to get vaccinated against COVID-19.
 - **[G]** Gender was not associated with whether respondents knew where they would need to go to get a vaccine by themselves.
 - **[D]** Respondents with a visual disability were more likely not to know where to go.
 - **Affordability**
 - **[A]** The **perceived** costs of health care and of transportation to the health centres did not appear to be a barrier associated with age.
 - **[G]** Similarly, they did not emerge as a major gender-related issue.
 - **[D]** Difficulties affording to reach or access a COVID-19 vaccine were associated with mobility and cognitive disabilities.

QUALITATIVE ANALYSIS:

Surprisingly, some participants reported still not having information about COVID-19 vaccination. Persons with disabilities reported feeling particularly at risk of contracting COVID-19, yet also facing restricted access to information as well as practical barriers to using health services. As expected, one of the main barriers was related to the costs of transportation to the vaccination sites without further assistance. Moreover, while routine child immunisation is understood and accepted, the same behaviour in favour of vaccination does not apply to COVID-19. Vaccine-related beliefs seem to be tied to previous experiences with health services—often, for Persons with disabilities, a lack of care or a low quality of care and of interactions with health staff. The health workers interviewed confirmed persons with disabilities' scarce attendance at health centres and reported needing Inclusive Health training. Religious leaders in the targeted communities are already promoting COVID-19 vaccination, probably thanks to the health programmes and information provided in the first two years of the pandemic. On the other hand, negative rumours still play a role, especially those about a supposed risk of infertility for people who get vaccinated against COVID-19. Persons with disabilities also voiced additional concerns about risking more potential side effects than others.

Conclusions

The first takeaway of this study is the astonishing lack of information about COVID-19 and vaccines among Persons with disabilities, which should motivate health actors to make further efforts to improve on their prevention campaigns and reach the most vulnerable populations. This study also shows how intersectionality between age, gender, and disability (plus the status as Internally Displaced Persons (IDPs) from rural areas) shapes beliefs about care-seeking. Some respondents among the most vulnerable groups knew next to nothing about COVID-19 vaccination and were fully excluded from health care, mainly because of a lack of information and of scarce (or negative, or expensive) past interactions with health services. Vaccination still remains out of reach for many, particularly due to associated costs. This is especially true for persons with disabilities, who, collectively, report barriers at multiple steps of the pathway toward quality care. Figure 2 below follows the pathway of accessing health care as described in the Missing Billion report.² The latter shows that, globally, persons with disabilities face higher health care needs, more barriers to accessing health services, and less health coverage, resulting in worse health outcomes. This study confirms this vicious cycle in the specific context of IDP camps in Somalia/Somaliland.

² Missing Billion Initiative (MBI), Clinton Health Access Initiative (CHAI). [Reimagining health systems that expect, accept and connect 1 billion people with disabilities](#) [Internet]. Seattle: MBI; 2022 Sept [cited 2023 Aug 3]. 36 p.

The top boxes highlight the barriers encountered, and the bottom boxes include quotations by participants and specify their gender, age, and disability type(s). This figure is not representative of all the diverse situations that exist: it only shows how important it is to identify barriers to access at multiple levels and act simultaneously upon them. Moreover, the qualitative data show once more that persons with disabilities in all their diversity are left aside in society. This means that immunisation for all depends on a broader approach to public health, with inclusive health policies, services, and information, and that these cannot be fully realized without deeper changes in society.

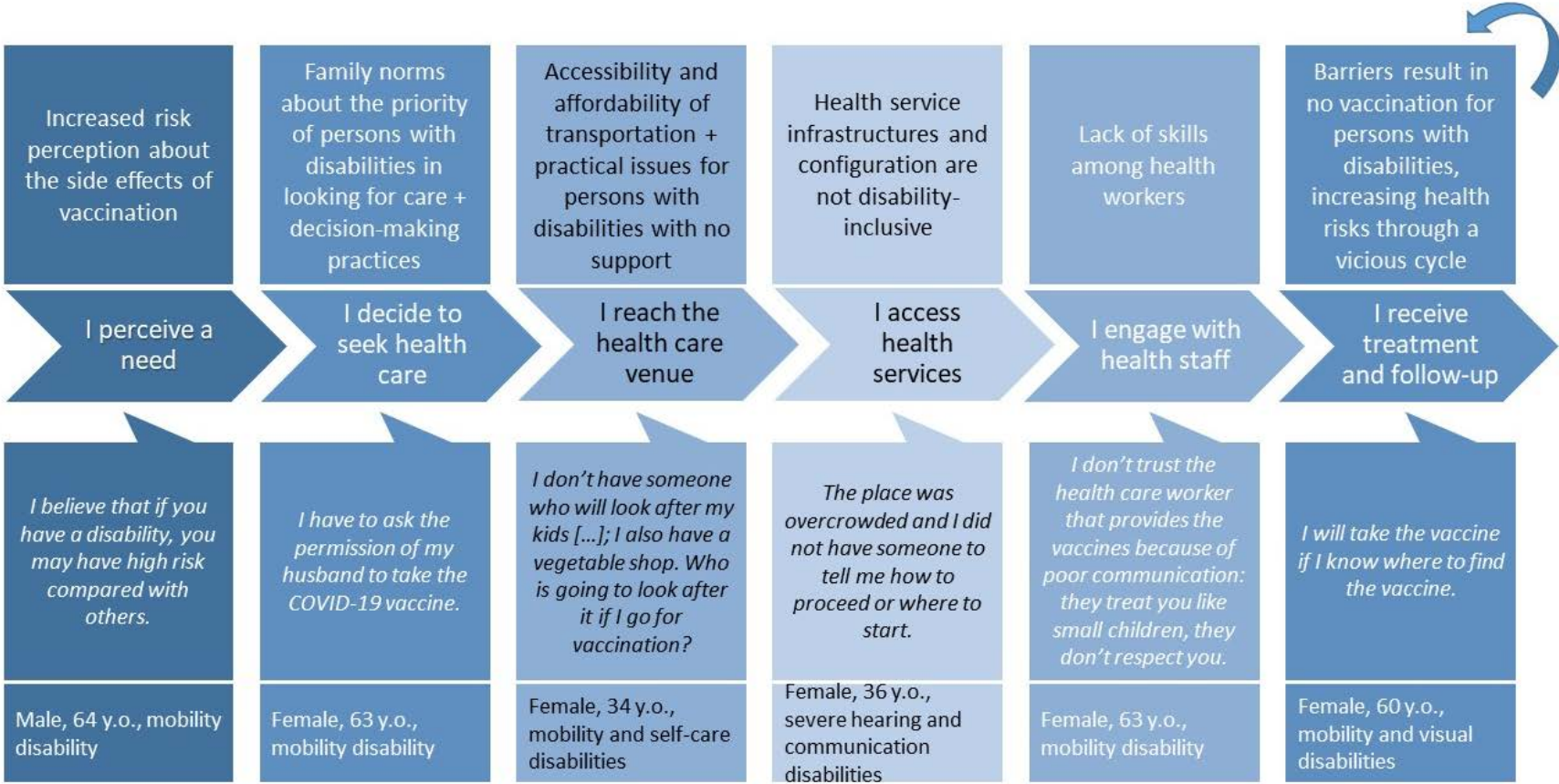


Figure 2: Barriers to accessing health services at different steps, with quotations from the study

Key recommendations

All in all, the evidence collected on the field for this study calls to strengthen advocacy for Inclusive Health in the context of immunisation by:

- Ensuring accessible and satisfactory experiences with health services, considering that past experiences using them create habits and become drivers of help-seeking;
- Bringing vaccination closer to disadvantaged areas and marginalised populations, thus facilitating access for persons with fewer possibilities of reaching health care centres or with limited mobility;
- Coupling vaccination with general medical services, considering that many persons with disabilities had had very limited prior access to health care despite their needs. It is pivotal to integrate vertical immunisation campaigns into the health care routine;
- Supporting social projects even when they are not directly related to vaccination, as it would contribute to reinforcing trust toward health actors and foster inclusive communities and solidarity, leaving no one behind.

This analysis shows how important it is to make sure to reach persons with disabilities and promote their meaningful participation in inquiries and research when identifying barriers and drivers of healthy practices. It is only through the active listening of Persons with disabilities by a trained team and by providing reasonable accommodation whenever necessary that we had the opportunity to spotlight this marginalised group's specific additional barriers to accessing health services, information, and prevention activities. Among the key lessons learned about how to conduct the inquiry phase of RCCE using the BeSD tools, we wish to stress the importance of:

- Training enumerators in Disability Inclusion;
- Facilitating the meaningful participation of Organizations of Persons with Disabilities (OPDs) in the adaptation and validation of the tools and results from the early phases on;
- Providing reasonable accommodation during data collection;
- Performing a disaggregated data analysis by age, gender, and disability by incorporating the WGQs into the socio-demographic data.

Making the case for Disability Inclusion in prevention

Inclusive Health is crucial for prevention

According to WHO,³ persons with disabilities—i.e., 1.3 billion people worldwide (16% of the world population)—too often suffer great inequities in accessing health services, from prevention to rehabilitation. Prevention and health promotion, which are key strategies against Emerging Infectious Diseases (EIDs), are the blind spots of accessibility. The SARS-CoV-2 pandemic offers a dramatic example, with persons with disabilities suffering disproportionately from the impacts of COVID-19 and related restrictive measures.⁴ During the pandemic, persons with intellectual disabilities were eight times more likely to die from the disease than those without intellectual disabilities.⁵ Achieving Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) (right to health)⁶ and the recent WHA resolution on the highest attainable standard of health for persons with disabilities⁷ requires an investment in strengthening health systems.

This action research project contributes to shining a light on needs and recommendations at the levels of different building blocks of health systems: service delivery (by reinforcing prevention), the health workforce (targeted in data collection), and information (by promoting disaggregated data by age, gender, and disability). More specifically, this project applied WHO's validated BeSD tools to identify the barriers and drivers of COVID-19 vaccination among a marginalised and vulnerable group in a specific context, adapting the tools for more inclusive future use. In the long term, this study contributes to achieving vaccine equity, leaving no one behind in EID prevention.

³ WHO. [Global report on health equity for persons with disabilities](#) [Internet]. WHO website. Geneva: WHO; 2022 [cited 2023 Aug 3]. 312 p.

⁴ International Disability Alliance (IDA). [IDA survey on the experiences of persons with disabilities adapting to the COVID-19 global pandemic](#) [Internet]. IDA website. Geneva: International Disability Alliance; 2021 [cited 2023 Aug 3]. 54 p.

⁵ WHO. [Global report on health equity for persons with disabilities](#) [Internet]. WHO website. Geneva: WHO; 2022 Dec 2 [cited 2023 Aug 3]. 312 p.

⁶ UN General Assembly. [Convention on the Rights of Persons with Disabilities \(CRPD\)](#) [Internet]. UN Department of Economic and Social Affairs website. 2006 Dec 13 [cited 2023 4 Aug].

⁷ WHA. [The highest attainable standard of health for persons with disabilities](#) [Internet]. WHO website. Geneva: WHA; 2021 May 31 [cited 2023 Aug 3]. 5 p. WHA74.8.

Barriers create disability

The Disability Creation Process⁸ (DCP) focuses on risk factors, personal factors, environmental factors, and life habits that could work as facilitators or enablers of participation since disability is the result of the interactions between all these elements that affect quality of life and inclusion in society on an equal basis. Moreover, disability is shaped by inequities in the Social Determinants of Health (SDHs)—such as health services, education, employment, housing, living conditions, etc.—often resulting in a cycle of poverty between disability and livelihoods. Conceptualizing Persons with disabilities' experience as a process, this framework points out that disability is determined by the presence of barriers at multiple layers of society, according to the socio-ecological (or social-ecological) model⁹: the individual, interpersonal, organizational, and community levels as well as that of public spaces. This reframing is crucial to going beyond the mere issue of the physical accessibility of health facilities by instead adopting a system suited to identifying and addressing the barriers to health where they really are.

Toward Inclusive Health Prevention using the BeSD tools

The BeSD model and tools applied in this study follow a clear theory of change focusing on multiple domains where persons with disabilities may encounter specific or additional barriers. These four categories (Thinking and Feeling; Motivation; Social Processes; and Practical Issues) may further be experienced in unique ways according to intersectionality (especially between gender, age, and disability). This study's hypothesis is that the drivers and barriers to vaccination are shaped in specific ways by the experience of living with a disability in a given socio-cultural context.

Ensuring Inclusive Health in vaccination implies a deep understanding of the specific, multiple, and interacting barriers potentially met by persons with disabilities. They turn the pathway to accessing health care into an obstacle course: Inclusive Health is not a single action, but a continued intentional effort in terms of policies and activities to tackle these barriers (including non-health factors) at different levels and steps. The inclusive use of the BeSD tools, adapted to have trained staff collect disaggregated data, allows to identify such barriers before launching an RCCE or Social and Behavioural Change Communication (SBCC) campaign. Although the pandemic has disproportionately affected persons with disabilities, 80% of whom live in low- and middle-income countries (LMICs), few studies provide

⁸ Fougeyrollas P, Boucher N, Edwards G, Grenier Y, Noreau L. [The Disability Creation Process Model: A comprehensive explanation of disabling situations as a guide to developing policy and service programs. Scandinavian Journal of Disability Research](#) [Internet]. 2019 Feb 14 [cited 2023 Aug 3];21(1):25-37.

⁹ Centers for Disease Control and Prevention (CDC). [The social-ecological model: A framework for prevention \[Internet\]. CDC website](#). 2022 Jan, 18 [cited 2023 Aug 4].

sufficient disaggregated data about them to support an inclusive response tailored for this group. In this respect, WHO recommends ensuring that immunisation monitoring systems collect age-, gender-, and disability-disaggregated data to measure equitable uptake and coverage over time by geography, population group, and risk group.¹⁰

In a world where we've just gone through a pandemic and where EIDs, particularly zoonoses, are an increasing concern, we learned that "No one is safe until everyone is safe." This means promoting Disability Inclusion in the research, design, implementation, and evaluation of RCCE and SBCC interventions against infectious diseases to make sure to leave no one behind.

¹⁰ WHO, UNICEF. [Disability considerations for COVID-19 vaccination: WHO and UNICEF policy brief, 19 April 2021](#) [Internet]. WHO website. Geneva: WHO and UNICEF; 2021 April 19 [cited 2023 Aug 3]. 17 p.

Part 1 – Introduction and context

1.1 Intersecting crises

Endemic inter-clan fighting for control of land, pastures, or water sources, a phenomenon intensified during drought conditions, continues to force civilians to flee. Insecurity also drives displacement and heightens humanitarian needs. The protracted internal displacement situation in Somalia/Somaliland has also led to a loss of social protection networks. However, the sustained period of political and institutional progress shows a country transitioning out of fragility and protracted crises. The Somali economy recovered from the recession in 2020 to register an estimated Gross Domestic Product (GDP) growth of 2.0% in 2021, driven by private consumption and livestock exports¹¹. Yet, multiple shocks including floods, locust invasions, and COVID-19 curtailed the pace of recovery and increased poverty to the point that, without humanitarian assistance, Somalia/Somaliland is projected to face its second famine in just over a decade.

1.2 COVID-19 in Somalia/Somaliland

Somalia/Somaliland did not rank high for the impact of COVID-19. Nevertheless, the pandemic exacerbated preexisting vulnerabilities, especially among certain groups, as well as fragilities in the health system. Indeed, the COVID-19 situation in Somalia/Somaliland has been difficult due to a combination of factors such as conflict, displacement, and limited health care infrastructures. The country has also faced significant challenges to implementing effective public health measures and providing adequate testing and treatment to those in need. WHO reported a total of 27,334 confirmed cases of COVID-19 in Somalia (see Figure 3). However, the excess death toll between January and September 2020 was 3,200-11,800: this let suppose a hidden excess mortality rate¹². Moreover, many people suffered and died in consequences of the Covid-19 effects on livelihood. These figures underline the devastating toll of COVID-19 on the country's population (17.07 million), including its dramatic negative effects on the livelihoods of many. The COVID-19 pandemic has had a catastrophic impact on education, health, nutrition, and protection for millions of people in Somalia. The communities at a high risk of COVID-19 are disproportionately affected, especially those who live in IDP camps as well as vulnerable host communities with limited access to health and sanitation services.

¹¹ The World Bank. [GDP growth \(annual %\)- Somalia](#). [Internet]. [Cited 2023 Aug 10].

¹² Warsame A, Bashiir F, Freemantle T, Williams C, Vazquez Y, Reeve C, Aweis A, Ahmed M, Checchi F, Dalmar A. [Excess mortality during the COVID-19 pandemic: a geospatial and statistical analysis in Mogadishu, Somalia. International Journal of Infectious Diseases](#) [Internet]. 2021 [cited 2023 Aug 10]; 113: 190-199.

1.3 COVID-19 vaccines in Somalia/Somaliland

Somalia/Somaliland was among the first African countries to receive doses of the COVID-19 vaccines through the COVAX facility. Vaccines are widely recognized as a major tool for achieving public health success against the pandemic. However, certain groups of people may have doubts about the benefits of the available COVID-19 vaccines and concerns about vaccine safety, causing them to question the need for vaccination—a motivational state known as “vaccine hesitancy.”¹³ The current literature shows disparities in vaccine acceptance across different geographical settings and population strata. All in all, the country has managed to fully vaccinate 30% of its population against COVID-19.

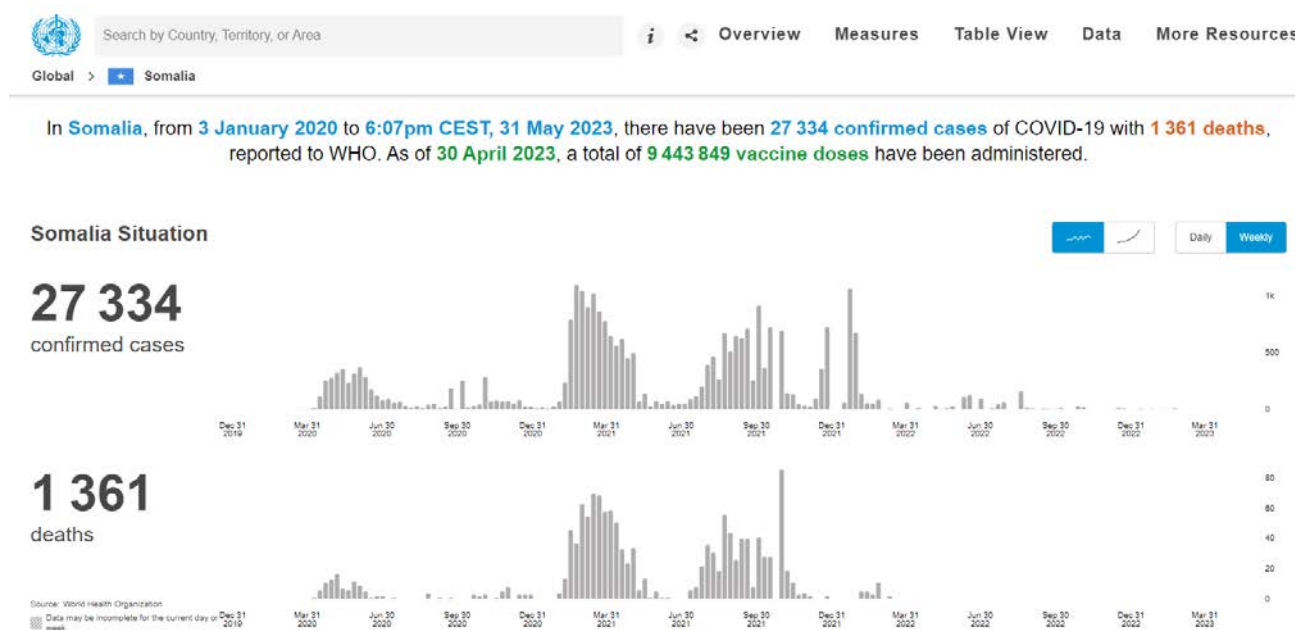


Figure 3: WHO’s dashboard of COVID-19 cases, mortality, and vaccination in Somalia¹⁴

¹³ WHO. [Behavioural and social drivers of vaccination: Tools and practical guidance for achieving high uptake](#) [Internet]. WHO website. Geneva: WHO; 2022 [cited 2023 Aug 3].

¹⁴ WHO. [Somalia situation](#) [Internet]. [WHO Health Emergency Dashboard](#) - WHO (COVID-19) Homepage. Geneva: WHO; 2023 [cited 2023 May 31].

Disaggregated data are not collected systematically in Somalia/Somaliland. In April 2020, Save the Children conducted in the whole country a Rapid Assessment based on a WHO tool for RCCE to understand, among other indicators, how children and adults with disabilities had received information on COVID-19.¹⁵ At the time, about 65% of the respondents reported that they did not have access to any information about the coronavirus in sign language or other accessible formats. This already demonstrated a lack of inclusive health information. Concurrently, other humanitarian actors¹⁶ conducted a similar assessment in the country with a specific focus on IDPs living in camps. Overall, the participants demonstrated a strong knowledge of how to prevent coronavirus transmission. At the time, persons with disabilities voiced concerns about deteriorating access to essential services. Another study, carried out in Somalia the following year (2021) and commissioned by CARE International¹⁷ after an intervention, reported that almost 99% of the participants had heard about the pandemic and 75% demonstrated correct handwashing practices, with 70% willing to get vaccinated against COVID-19.

¹⁵ Save the Children International, [Save the Children Somalia/Somaliland](#). Risk Communication & Community Engagement (RCCE): [Somalia COVID 19 Rapid Assessment Survey Report](#) [Internet]. Save the Children Child Rights Resource Centre website. London: Save the Children International; 2020 April [cited 2023 Aug 3]. 16 p.

¹⁶ Camp Coordination Camp Management (CCCM) Cluster, Displacement Tracking Matrix (DTM) Somalia. [COVID-19 response: RCCE Feedback Assessment in IDP sites – Round 2 Somalia](#) [Internet]. UN High Commissioner for Refugees (UNHCR) Operational Data Portal (ODP) website. Geneva: CCCM Cluster; 2020 Sept [cited 2023 Aug 3]. 15 p.

¹⁷ Hygiene and Behaviour Change Coalition (HBCC), UK Aid, Unilever, CARE International. [End line review for HBCC project: Inclusive communities: Changing behaviours to respond to COVID-19 - Final Report](#) (August 2021) [Internet]. UN ReliefWeb website. Geneva: CARE International; 2021 Aug 1 [cited 2023 Aug 3]. 25 p.

Part 2 – Methodology

2.1 Design of the study

This study collected primary data from persons with disabilities via both quantitative and qualitative methods.¹⁸

For the quantitative data, the adopted method was the simplest level of statistical inquiry via bivariate analyses, which provide information about the relationships between two variables using Pearson’s chi-square and thus, allow to explore correlations. In this way, we compared and examined the relationships between age, gender, and disability type on the one hand and each priority indicator on the other hand.

A qualitative analysis¹⁹ further enabled us to capture holistically the experience of this project’s specific target population: adults with disabilities who were internally displaced. The choice of this method was motivated by the overall goal of understanding the meaning of barriers in each PwD’s unique situation in the special context of Somalia/Somaliland. According to the literature, qualitative research has often been used to investigate perceptions and experiences regarding vaccination.²⁰ In practical terms, this approach is particularly useful for recording the exact wordings used by the local populations who will be the targets of further RCCE activities and health promotion campaigns. Moreover, the quantitative survey method may present additional barriers for persons with some communication disabilities, who may feel overwhelmed when participating in in-depth interviews—either directly or via their caregivers.

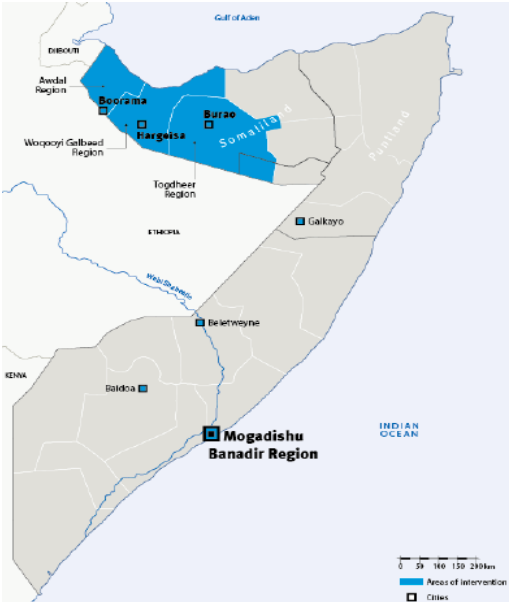
¹⁸ Ozawa S, Pongpirul K. [10 best resources on... mixed methods research in health systems](#). Health Policy and Planning [Internet]. 2014 May [cited 2023 Aug 4];29(3):323-327.

¹⁹ Hudelson, PM, WHO. [Qualitative research for health programmes](#) [Internet]. WHO website. Geneva: WHO; 1994 [cited 2023 Aug 4]. 102 p. WHO/MNH/PSF/94.3.

²⁰ Oku A, Oyo-Ita A, Glenton C, Fretheim A, Ames H, Muloliwa A, Kaufman J, Hill S, Cliff J, Cartier Y, Owoaje E, Bosch-Capblanch X, Rada G, Lewin S. [Perceptions and experiences of childhood vaccination communication strategies among caregivers and health workers in Nigeria: A qualitative study](#). PLoS One [Internet]. 2017 Nov 8 [cited 2023 Aug 4];2(11).

2.2 Locations of the study areas

According to HI's experience in this country and similar settings, Persons with disabilities who are displaced or migrants are among the most vulnerable groups in terms of access to health. Due to the location of the IDP camps and the rules limiting access to them, reaching these groups is not easy for the health workforce, and even national health programmes often do



not include them. Therefore, according to humanitarian principles, HI decided to spotlight this population's access to COVID-19 vaccines. The survey respondents came from the Kahda (50%), Ayah3 (44%), and Caroyambo (6%) IDP camps. Out of a total population of 1,000 IDPs, we reached 277 participants for the quantitative survey, most of whom came from urban areas (94%). Only a few (6%) came from rural areas. The interview participants came from Mogadishu (Kahda) and Hargeisa (Malawle, Ayah3, and Caroyambo). The health workers interviewed came from 11 primary health care facilities and 1 hospital.

Figure 4: Map of Somalia/Somaliland

2.3 Individual selection

Being part of the local communities, the camps' community leaders are the natural gatekeepers to access the households of our targeted group. HI's team met them a few times to identify and reach the population of interest through snowball sampling. Once a household with a person with disability was identified, the data collectors used the WGQs to assess his or her disability status.

In accordance with the research protocol, the targets of the quantitative and qualitative research were Persons with disabilities aged 18 and above, both male and female, who were IDPs in two geographical areas, whatever the type or severity of their functional difficulties.

To facilitate data collection in the health centres during operating hours, the health workers were invited to the interviews according to their availability during the data collectors' days of visit to the health care venues. For practical reasons, only 12 health workers were asked about the topic of Disability Inclusion in addition to the standard BeSD interview for health workers.

2.4 Profiles of the respondents

All the persons included in the sample were adults self-reporting disabilities according to the WGQs. The tables below present the participants' profiles by age, gender, and disability included in the sample.

Most of the respondents to the quantitative survey (39%) were aged 30-49 years. Others were in the 50-69 (26%) and 18-29 (21%) age brackets. Only a small percentage (13%) was aged 70 and above.

Due to the sampling procedure, over half of the respondents (51%) were female and 49% were male.

Survey	AGE				Total (N)	%
GENDER	18-29 years	30-49 years	50-69 years	70+ years		
Female	30	54	37	19	142	51
Male	29	54	36	18	135	49
Total	59	108	73	37	277	100
%	21	39	26	13		

Table 1: Number of survey respondents by age group and gender

Based on the WGQs, those who reported “a lot of difficulty” (level 3 on a scale of 4) or “cannot do at all” (level 4) presented the following disabilities by gender:

- Vision: 19% of females and 23% of males reported having a lot of difficulties or a severe disability even while wearing glasses;
- Hearing: 18.3% of females and 7.4% of males had a lot of difficulties even with a hearing aid;
- Mobility: 30.3% of females and 31.1% of males encountered a lot of difficulties;
- Cognition: 20.4% of females and 23% of males experienced a lot of difficulties with cognition and remembering;
- Self-care: 23.9% of females and 27.4% of males reported a lot of difficulties with self-care tasks like washing up and dressing;
- Communication: 20.4% of females and 17.8% of males had a lot of difficulties communicating.

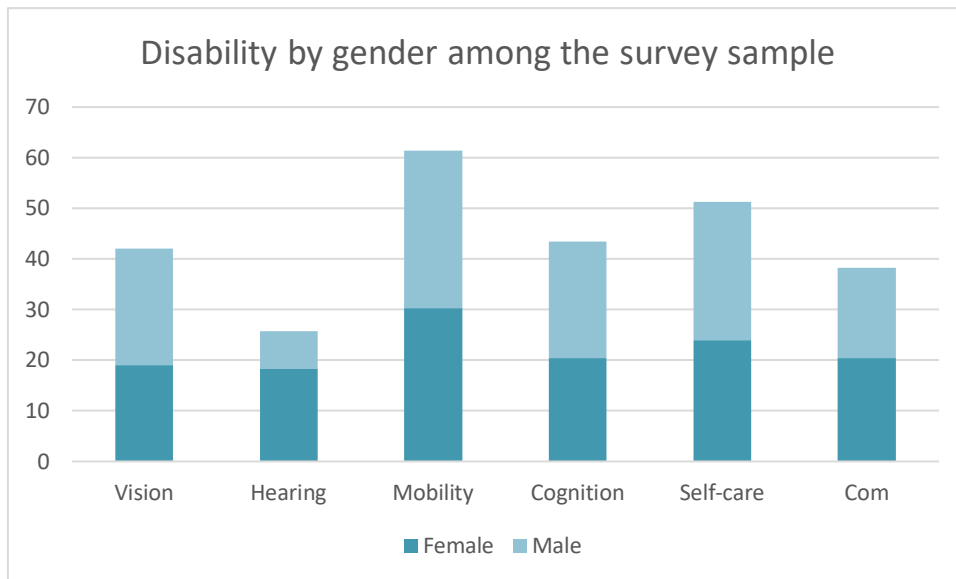


Figure 5: Disability by gender among the survey sample

Over half of the respondents (56%) said that they did not have a chronic condition. They made up 20% of the persons with disabilities aged 18-29; 33% of those aged 30-49; 34% of those aged 50-69; and, as expected, 49% of those aged 70 and above. On average, slightly more females than males had one or several chronic conditions (33.1% of females and 32.6% of males).

Most of the respondents (88%) stated that they had never had COVID-19. Among the 12% who reported having contracted it, 68% had developed a severe form. However, most of those who reported contracting the infection had not had it confirmed by a test (85%).

Most of the respondents (79% of females and 79% of males) stated that they had not received a COVID-19 vaccine. Among those who had been vaccinated, some had received one dose (13%); others, two doses (7%); and the rest, three or more doses (1%).

The following table presents an overview of the quantitative survey sample by age, gender, and disability, considering that 86% of the total reported two or more disabilities:

DISABILITY (number of participants)		AGE/GENDER							
		18-29 years		30-49 years		50-69 years		70+ years	
		M	F	M	F	M	F	M	F
Vision	No or few difficulties	23	27	40	34	24	20	5	7
	A lot of or severe difficulties	4	5	0	0	0	0	0	0
Hearing	No or few difficulties	23	27	49	41	30	23	12	11
	A lot of or severe difficulties	4	5	6	12	7	13	4	10
Mobility	No or few difficulties	14	21	37	31	20	25	7	6
	A lot of or severe difficulties	13	11	18	22	17	15	9	15
Cognition	No or few difficulties	20	25	37	31	20	25	7	8
	A lot of or severe difficulties	7	7	18	22	17	11	9	13
Self-care	No or few difficulties	19	21	31	36	25	22	6	7
	A lot of or severe difficulties	8	11	24	17	12	14	10	14
Comm.	No or few difficulties	20	19	33	34	22	19	8	16
	A lot of or severe difficulties	7	13	22	19	15	17	8	5

Table 2: Number of survey respondents by disability, age, and gender (with some having multiple disabilities)

Persons with disabilities (number)	AGE				Total	%
	18-29 years	30-49 years	50-69 years	70+ years		
GENDER						
Female	3	7	8	0	18	60
Male	2	5	5	0	12	40
Total	5	12	13	0	30	
%	17	40	43	0		

Table 3: Number of persons with disabilities interviewed by age group and gender

All the respondents to the interview reported at least one disability evaluated at least 3 on the WGQ scale; 13 reported multiple disabilities, at least one of which was severe (level 3 on a scale of 4). Among the interview sample, 9 persons reported a disability evaluated 4, the highest functional limitation on the WGQ scale.

DISABILITY (number)	AGE/GENDER					
	18-29 years		30-49 years		50-69 years	
	M	F	M	F	M	F
Vision	0	1	1	3	0	3
Hearing	0	1	0	1	1	3
Mobility	1	1	3	3	3	8
Cognition	0	1	3	0	0	1
Self-care	1	0	1	2	1	0
Communication	2	1	1	0	0	0

Table 4: Number of persons with disabilities interviewed by disability, age, and gender

The health workers we reached presented diverse professional profiles: nurses (16), nurse epidemiologists (EPI) (4), medical doctors (2), auxiliary nurses (2), Infant and Young Child Feeding (IYCF) nurses, (2), Opioid Treatment Programme (OTP) nurses (2), midwife (1), and Public Health Officer (1).

Health workers (number)	AGE					Total	%
	18-29 years	30-49 years	50-69 years	70+ years			
GENDER							
Female	11	11	1	0	23	77	
Male	2	4	1	0	7	23	
Total	13	15	2	0			
%	43	50	7				

Table 5: Number of health workers interviewed by age and gender

2.5 Tools and modalities

The BeSD of vaccination tools were developed by a WHO-led global working group to support programmes and partners in assessing and addressing the reasons for under-vaccination for both childhood and COVID-19 immunisation. For the needs of this study, the research team adapted three BeSD tools: the survey, the in-depth interview guide for adults, and the in-depth interview guide for health workers (version 1.0). The adapted versions did not change the five BeSD priority indicators nor the selected questions. However, some questions were removed to shorten interview time, and a few probing questions about disability-related issues were added. Moreover, the Washington Group short set (WG-SS)²¹ was also included into the socio-demographic data to disaggregate them by disability type.

The survey and the scripts for the interviews were translated into Somali then back into English under the supervision of one of the researchers. In accordance with the cognitive interview guidelines from the BeSD manual, a meeting was organized with two representatives from two OPDs to collect their feedback about the survey and the questionnaire.

The piloting of the quantitative survey consisted in 15 interviews with persons with disabilities in one day followed by a debriefing with one of the researchers. Before data collection, the enumerators (11 persons) had been trained by the researcher in Inclusive Communication and on using the BeSD tools. Data collection was carried out face-to-face in the IDP camps in 14 days after authorization by the camp managers. To ensure equal participation, reasonable accommodation was allocated to persons with different disabilities, including household visits, involving caregivers when needed, and allotting extra time when needed.

²¹ Washington Group on Disability Statistics (WG). [The Washington Group short set on functioning \(WG-SS\)](#) [Internet]. WG website. 2022 Oct 11 [cited 2023 Aug 4]. 3 p.

2.6 Analysis

The quantitative analysis is descriptive then bivariate, using Pearson's chi-square test and disaggregated analysis by age, gender, and disability. The survey was designed to generate a 95% confidence level and 5% margin of error for each population group in the target locations.

The qualitative analysis applied framework analysis, an established method of data analysis, because it is flexible yet rigorous. Two researchers of different genders, ages, backgrounds, languages, and nationalities analysed the interviews—one researcher, in the local language and the other, in the English translation. The analysis of the interviews of health workers was then conducted based on the English translation. An initial list of codes had been retrieved from the Knowledge, Attitudes and Practices survey and the Vaccine Acceptance dashboard of the Johns Hopkins University²² and clustered according to the BeSD framework.

2.7 Limits

Among limits, the interview and the survey were conducted almost in parallel. As a result, the survey team could not be informed by the benefits of the interviews. Moreover, by design, it would be difficult to generalize these data to other contexts and it is not the goal of this study. Finally, both researchers who authored the qualitative analysis work for the non-governmental organization that carried out the research project.

2.8 Ethical aspects and conflict of interests

The study was coordinated with the relevant stakeholders to avoid unnecessary duplication of data collection efforts. Basic information about COVID-19 vaccination was delivered just after data collection when requested. Respecting the respondents' rights and dignity, the team always asked for informed consent as a prerequisite. To ensure equal participation whatever the disability or disabilities, reasonable accommodation was given to persons with different disabilities. In addition, the study guaranteed that neither the data collectors nor the respondents and their communities were exposed to risks as a result of their direct participation in data collection. The enumerators were taught on data collection ethics for questions related to sensitive protection issues to make sure that questions were asked in a non-sensitive manner to mitigate any unintended harm to vulnerable groups. The design of the study further ensured that there was no data collection involving anyone below 18 years old. All of HI's Standards Operating Procedures (SOPs) were also adhered to throughout the study. Finally, HI ensured the security of personal and/or sensitive data at all stages of the activity.

²² Johns Hopkins Center for Communication Programs. [KAP COVID global view](#) [Internet]. Johns Hopkins Center for Communication Programs website. 2021 Sept [cited 2023 Aug 4].

All the anonymized quotes in this report were translated into English by the researchers, keeping the original formulations and word choice.

This study was funded by the Universal Health Coverage and Life Course (UHL) division of WHO's Immunization, Vaccines and Biologicals (IVB) department, Geneva. HI carried out several programmes in the country, including an RCCE project to foster the right to health as well as access to COVID-19 vaccination.

Reflexivity on inclusive data collection: The voices of the team

At the end of data collection, a 2-hour focus group was carried out online with the HI staff involved in the process (enumerators and interviewers) to obtain insights on what engaging Persons with disabilities in a study using the BeSD tools could mean in a real-life pilot project.

Access to participants:

The modality chosen to reach the target populations did not always work smoothly due to general misinformation about what disability is: *“For community leaders, all elders are persons with disability”*—ignoring youths and younger adults with disabilities. During household visits, the relationship with the caregiver(s) was considered very important because they may act as gatekeepers: *“Two caregivers refused the meeting because of their expectations for concrete support.”* However, it is also important to remember that persons with disabilities do not always need a caregiver. On the contrary, *“some PwD are the head of the household and the breadwinners”*; for this reason, they were out during the day, but access to the sites was not allowed in the evening for security reasons. Despite the importance of caregivers when present, it is crucial to listen to persons with disabilities directly: *“We always asked to caregivers the permission, but only in few cases we interviewed the caregivers only”*; *“Usually, caregivers were not in the room during the interview, but sometimes it could happen; in one case, with a person with hearing disabilities, the caregivers tended to fill the sentences instead of the person.”* When present, caregivers may support the staff: *“In one case, the presence of the caregiver was requested, she helped in translating with sign language.”* However, we do not recommend counting on caregivers to offer reasonable accommodation because this could result in an extra burden and loss of time for them.

Obtaining free consent:

According to the experience of the staff, *“in general obtaining consent was quite smooth, once translated and well explained.”* However, some enumerators reported that *“it was not easy for persons with some disabilities to understand, especially for those with low literacy for whom even the topic was too complicated, many had no*

idea of COVID-19.” The way to present the study was culturally adapted, but some misunderstanding still remained, as analysed by medical anthropologists in other contexts.²³ This calls for rethinking self-presentation and how to approach some groups. Because of their difficulties understanding the aim of the study and the questions, *“some participants were reluctant or stressed,”* although others were *“happy to speak for the first time with NGO staff.”* This leads to the conclusion that it depends on the skills of the interviewer, who should *“let people ask questions too.”* Stress also stemmed from the fact that *“IDPs are new in the camps, they do not understand why we are asking them those questions, they feel fear.”*

Interacting with persons with specific disabilities:

Despite their initial short training, the staff felt challenged by their interactions with this group overall, especially persons with cognitive or psychosocial issues or with *“intellectual or communication disabilities because they were less focused, often out of topic.”* For some, it was their first real contact with Persons with disabilities (*“for many, it was the first time interacting with persons with disabilities.”*)

They also found it difficult to interact with persons with poor hearing or with visual disabilities as well as with persons with multiple disabilities, which demonstrates the importance of including more role-plays into the capacity-building activities to make sure that the staff feel comfortable dealing with specific needs.

They reported having learned a lot by doing: *“We learned to be patient”*; *“We learned to understand their past negative experiences with other organizations that influenced our work.”*

Making data collection inclusive:

According to the staff’s experience, forms of reasonable accommodation that were put into place in some cases and that they found useful in these situations include:

- Having a sign language interpreter;
- Dedicating extra time to the meeting and having a short script;
- Asking for help from caregivers;
- Receiving training in Inclusive Health and inclusive data collection;
- Mobilizing the community to build trust in advance;
- Using visual supports;
- Finding the right place, not at home or in a tent (as they were often crowded) but not far from where the person lives.

²³ Zaman S, Nahar P. [Searching for a lost cow: Ethical dilemmas of doing medical anthropological research in Bangladesh](#). *Medische Antropologie* [Internet]. 2011 [cited 2023 Aug 4];23(1):153-163.

Using the BeSD tools with persons with disabilities:

According to their experience on the field, the team suggested the following:

- Making the tools shorter and simpler (*“mentioning different types of vaccines was confusing”*);
- Investing more time into the pilot phase;
- Involving more OPDs in the adaptation of the questions and options for response;
- Using the tools at the right time: *“People do not remember now that COVID-19 is ended”*;
- In addition, some questions were perceived as too similar, as they prompted repetitions instead of new information.

Recommendations for future use of the BeSD tools with persons with disabilities:

Reflecting on what could be done better in the future, the staff suggested the following:

- Receiving a longer training in Inclusive Health;
 - Hiring persons with disabilities as part of the team;
 - Preparing reasonable accommodation in advance;
 - Involving the host communities as well and offering incentives for participation;
 - Using results from disaggregated data analysis to demonstrate health inequities and advocate for the rights of persons with disabilities.
-

Part 3 – Findings and discussions

3.1 Quantitative findings

Thinking and Feeling

Confidence in COVID-19 vaccine benefits

Age: When the respondents were asked about the importance of COVID-19 vaccination for their health, 40.8% said that it was very important—especially those aged 18-29 years (52.5%). However, it is worth noting that 21.7% of the respondents, especially those aged 70 and above, stated that the vaccines were not important at all. The perceived importance of COVID-19 vaccines decreased as persons advanced in age (statistically significant association).

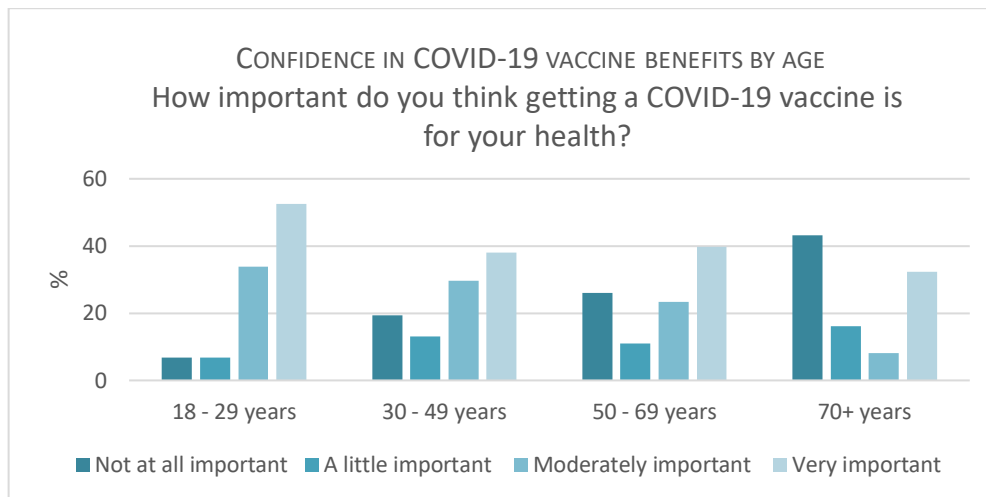


Figure 6: Confidence in COVID-19 vaccine benefits by age

Gender: When the respondents were asked about the importance of COVID-19 vaccination for their health, 33.8% of females and 48.1% of males said that it was very important. However, some (24.6% of females and 18.5% of males) stated that it was not important at all.

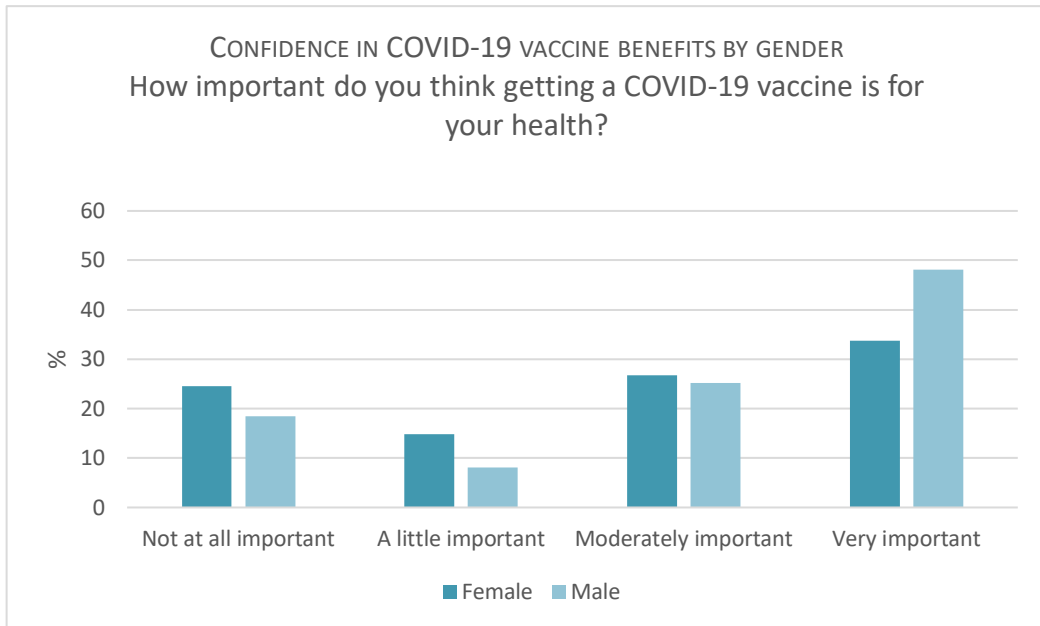


Figure 7: Confidence in COVID-19 vaccine benefits by gender

Disability: 40.8% of the persons with disabilities surveyed said that getting vaccinated against COVID-19 was very important for their health. We also found a statistically significant association between the perceived importance of COVID-19 vaccination and the degree of self-care disabilities among those whose disabilities affected self-care practices and possibilities.

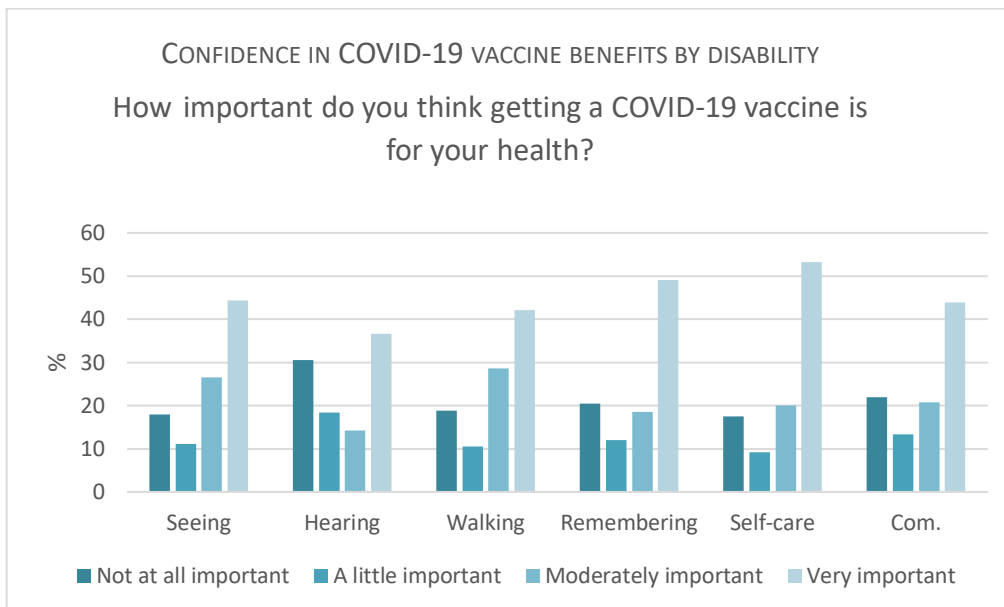


Figure 8: Confidence in COVID-19 vaccine benefits by disability

Confidence in the safety of the COVID-19 vaccines

Regarding opinions about the safety of the COVID-19 vaccines, 36% of the respondents (29.6% of females and 42.2% of males) believed that they were very safe while 20% said that they were not safe at all, especially those aged 70 and above (45.9%).

Confidence in health workers

The respondents were also asked how much they trusted the health workers who would administer the vaccines: 42% trusted them very much; 13%, a little; and 18%, not at all. Respondents aged 70 and above mostly (35.1%) did not trust health workers.

Motivation

Intention to get a COVID-19 vaccine

Age: The respondents who were not already vaccinated were asked if they wanted to get a COVID-19 vaccine: over half of them (56.7%) wanted to, making up 67.8% of those aged 18-29 years; 60.2% of those aged 30-49 years; 53.4% of those aged 50-69 years; and 35.1% of those aged 70 and above. On the other hand, 13.3% were hesitant and 30% did not want to get vaccinated—mostly those aged 70 and above (59.5% of this age group). None of those who were vaccinated was aged 70 and above.

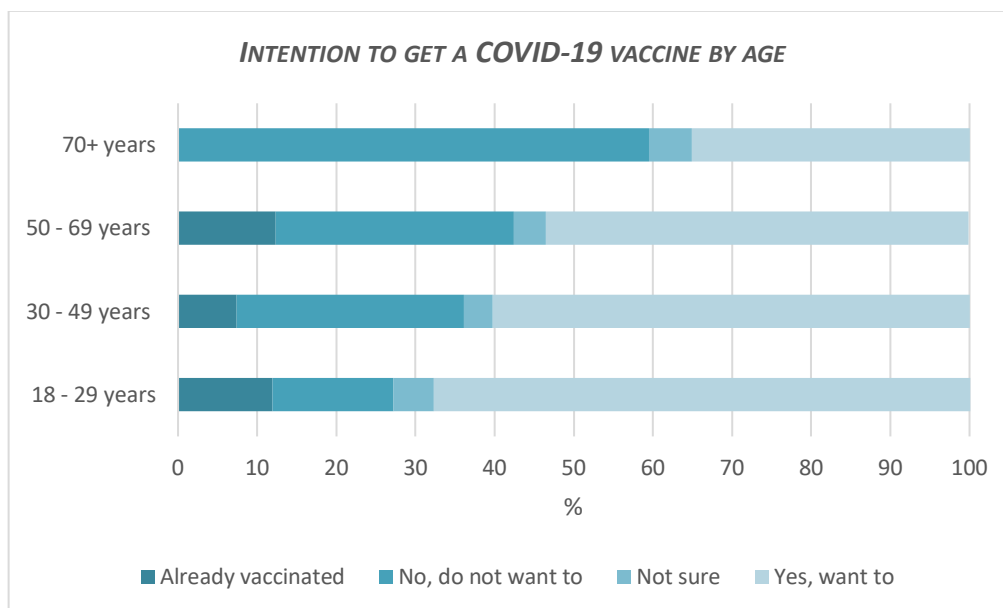


Figure 9: Intention to get a COVID-19 vaccine by age

Gender: Disaggregating the motivation to get vaccinated revealed that 47.9% of females and 65.9% of males wanted to. These results show that males were more likely to want a COVID-19 vaccine than females (statistically significant association).

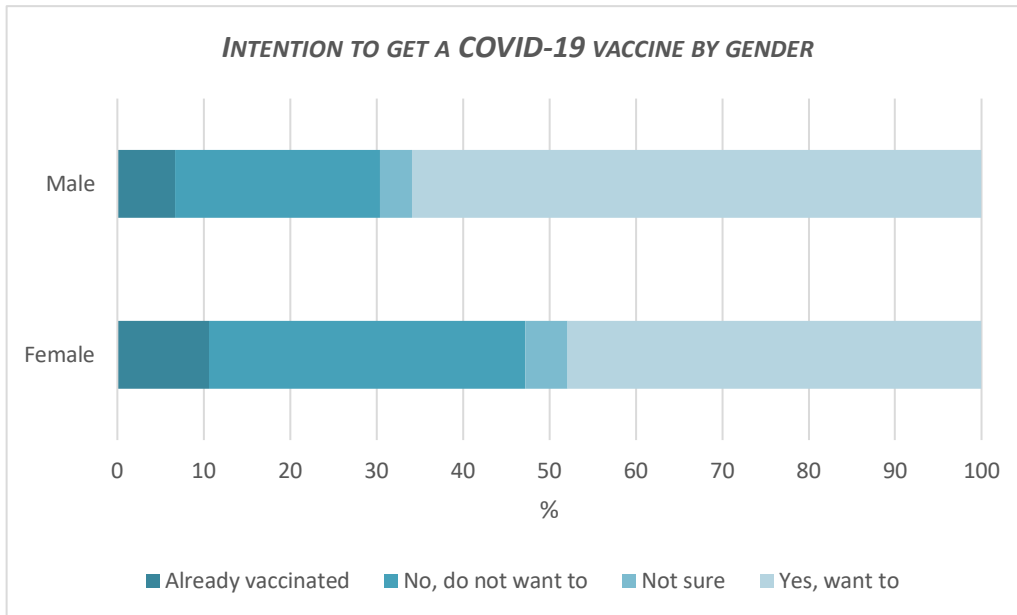


Figure 10: Intention to get a COVID-19 vaccine by gender

Disability: There was no statistically significant association between the motivation to get a COVID-19 vaccine and visual, hearing, mobility, cognitive, self-care, or communication disabilities.

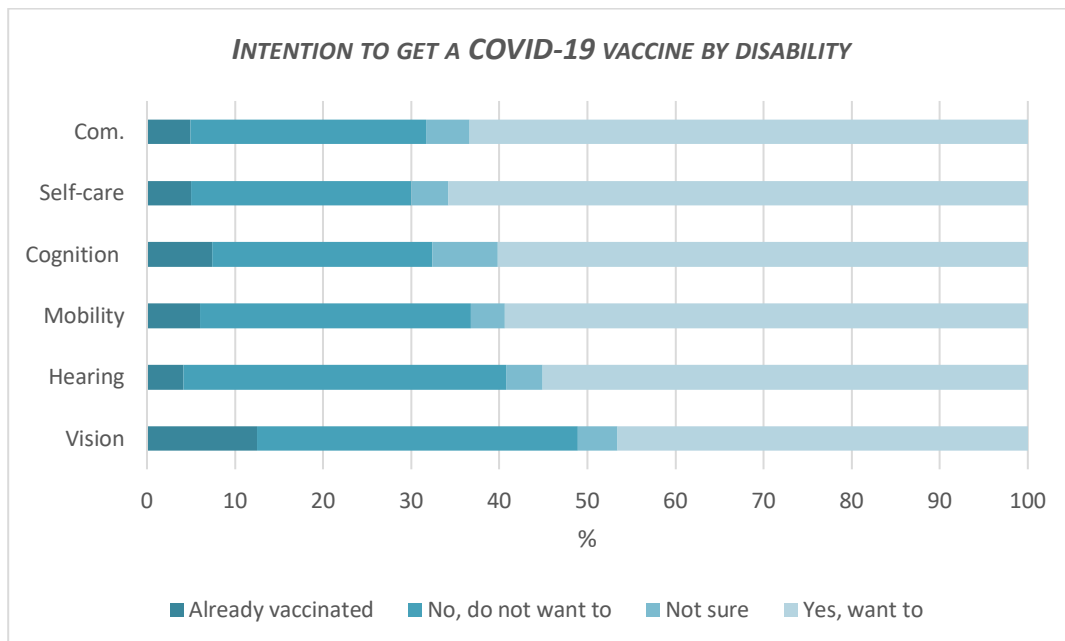


Figure 11: Intention to get a COVID-19 vaccine by disability

Social Processes

Peer norms

Most of the respondents (60%) thought that other adults in their relationship network would recommend them to get a vaccine.

Family norms

Age: When the respondents were asked if most of their close family and friends wanted them to take a COVID-19 vaccine, 61.7% answered in the positive. The respondents from this group were mainly aged 18-29 years (71.2%). These results show that younger persons were more likely to be influenced by their family and friend circle (statistically significant association).

Gender: 57.7% of females and 65.9% of males answered that most of their family and friends wanted them to get vaccinated.

Disability: Whatever their disability type, most of the respondents thought that most of their close family and friends wanted them to get a COVID-19 vaccine. Those who had this perception made up 65.8% of those with self-care disabilities; 64.6% of those with communication disabilities; 63.9% of those with cognitive disabilities; 60.9% of those with mobility disabilities; 59.2% of those with hearing disabilities; and 51.1% of those with visual disabilities.

Gender equity-travel autonomy

As for the other social processes and norms investigated, most respondents (52.1% of females and 57% of males) said that they would need permission to get vaccinated.

Religious leaders' norms

Over half of the respondents (56%) said that religious leaders would want them to get vaccinated against COVID-19.

Health workers' recommendations

When asked if health workers had recommended that they take a COVID-19 vaccine, 64% of the respondents (60.6% of females and 68.1% of males) said that they had.

Practical Issues

Knowing how to get vaccinated

Age: When asked if they knew where they would need to go to get a COVID-19 vaccine by themselves, most of the respondents (66.8%) answered in the negative. Those who did not know where to go were mainly aged 70 and above (81.1%).

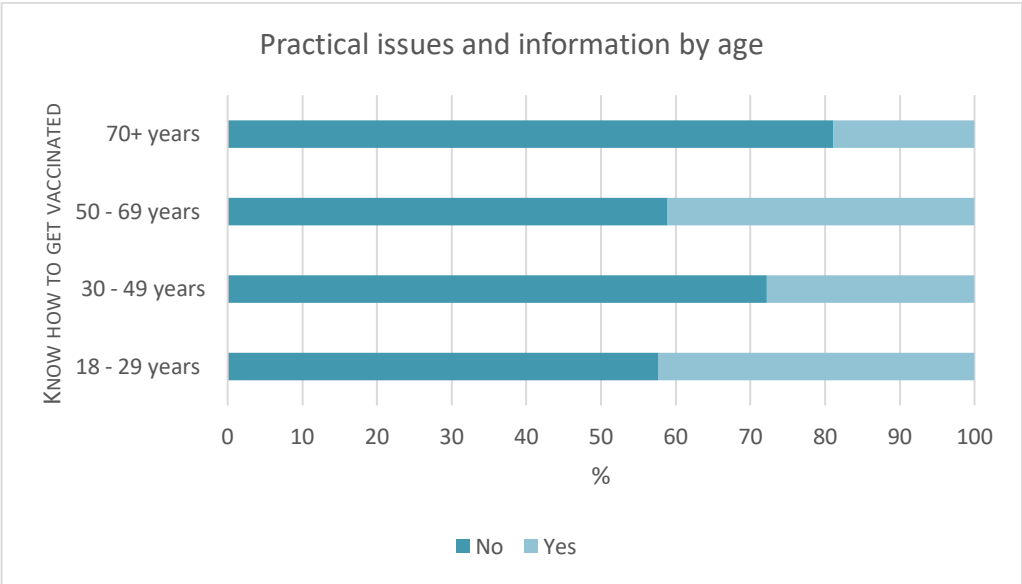


Figure 12: Practical issues and information by age

Gender: 71.1% of females and 62.2% of males did not know where to go to get vaccinated.

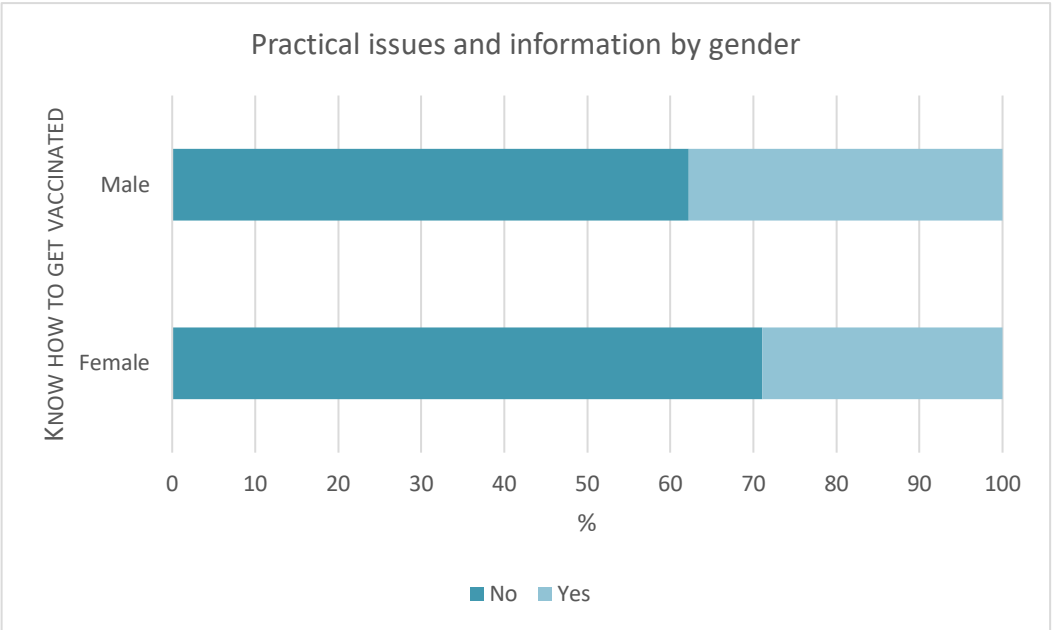


Figure 13: Practical issues and information by gender

Disability: Most of the persons with disabilities surveyed did not know where to go to get vaccinated against COVID-19. The figures according to disability type are as follows: 76.1% for vision; 70.7% for mobility; 65% for self-care; 64.8% for cognition; 63.3% for hearing; and 63.4% for communication. These results show that persons with visual disabilities were more likely to be unaware of where to go (statistically significant association).

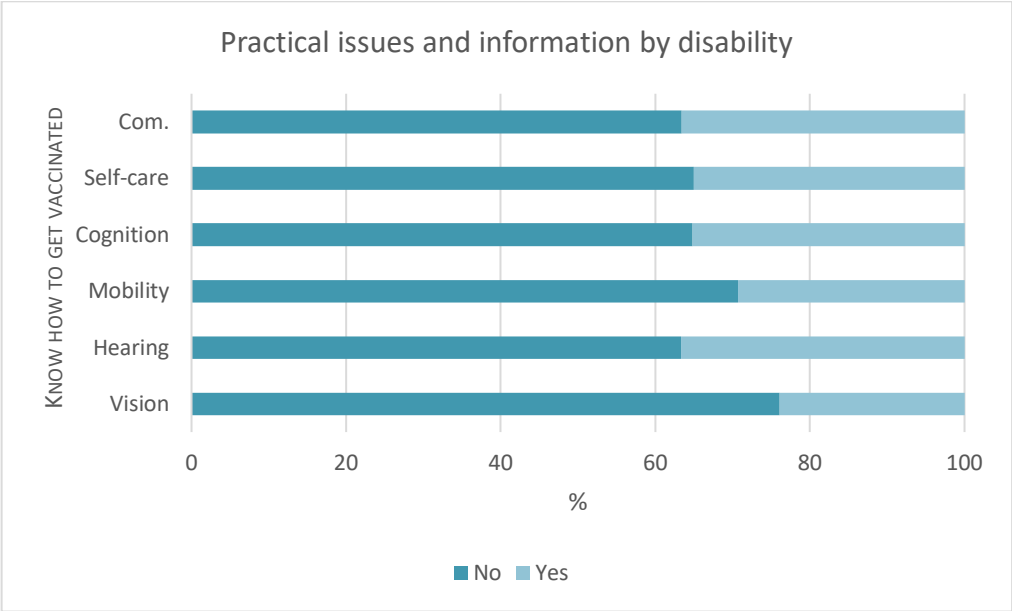


Figure 14: Practical issues and information by disability

Affordability

Age: The costs of vaccination (including cost of transportation) mainly affected those aged 70 and above (81.1%), those aged 30-49 years (75.9%), and those aged 50-69 years (71.2%).

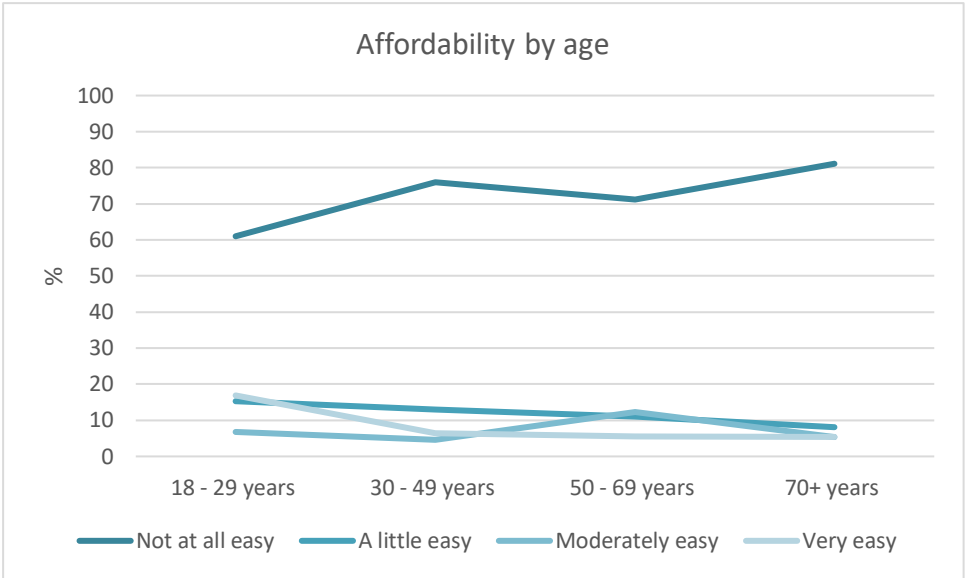


Figure 15: Practical issues and affordability by age

Gender: Females (75.4%) were more likely to experience difficulties affording vaccine-related costs (including transportation) than males (68.9%).

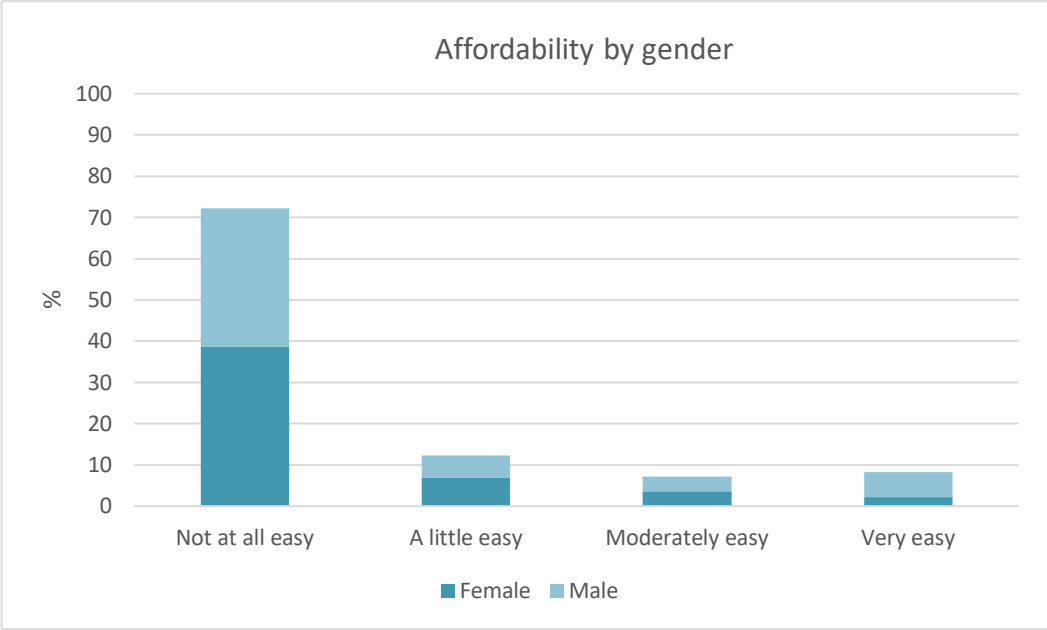


Figure 16: Practical issues and affordability by gender

Disability: Paying for a COVID-19 vaccine or to reach the centre was not easy at all for 72.2% of the respondents regardless of disability type.

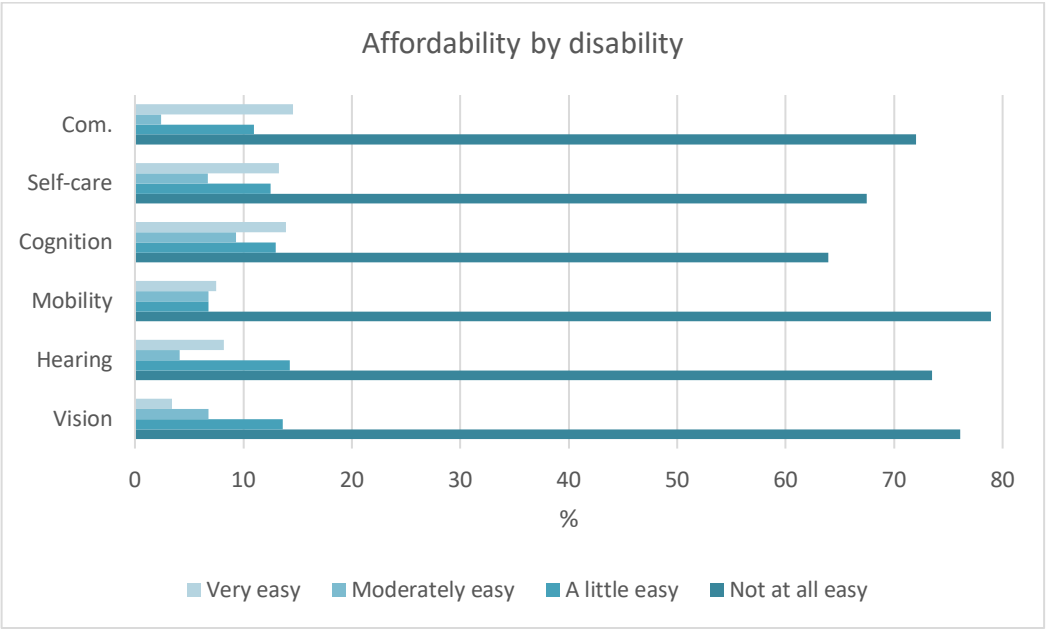


Figure 17: Practical issues and affordability by disability

Ease of access

Regarding the reasons for inaccessibility or low ease of access to vaccination, 46% of the respondents (52.8% of females and 39.3% of males) said that COVID-19 vaccination was not yet available to them; 44%, that the vaccination sites were hard to reach; and 16%, that making an appointment was difficult.

Service satisfaction

Concerning satisfaction with COVID-19 vaccination services, 33.9% of the respondents (30% of females and 37.9% of males) were very satisfied.

3.2 Qualitative findings

“Every disease has a treatment, but you can die from lack of medicine.”

(Female, 36 y.o., severe hearing and communication disabilities)

Thinking & feeling

Perceived risk - self

Thinking and feeling are embodied in each persons' situation. This means that the subjective experience of a situation like the pandemic health emergency depends on each person's unique experience of their own body and capabilities. Almost all the participants who lived with one or several severe disabilities agreed that Persons with disabilities were more at risk than others of catching the coronavirus: ***“We're vulnerable to diseases and we're affected more than others, we're weak”*** (male, 54 y.o., mobility disability).

This belief about being at risk was also linked to some persons with disabilities' need for extra support by caregivers—which was, however, not always available: ***“I am afraid of getting any disease because I am alone, I have no one to assist me”*** (female, 60 y.o., visual disability). Reliance on caregivers shapes the perception of health needs as well as the care-seeking behaviour: ***“I feel like I am a burden to my family, sometimes; if I tell them that I am sick, they say it is in my mind”*** (male, 45 y.o., cognitive and communication disabilities).

Clearly, as generalization and stigma may obscure, not all persons with disabilities need a caregiver; on the contrary, some are breadwinners and/or caregivers for their own relatives, which places additional responsibilities on their shoulders: ***“My children only have me and I feared if I get the disease and die, who is going to look after them?”*** (male, 41 y.o., severe mobility and cognitive disabilities); ***“I already have difficulty in taking care of my children, I don't want to add another burden to them”*** (female, 34 y.o., mobility and self-care disabilities).

Such considerations often extended to the potential side effects of the vaccines, providing an additional argument against them: ***“I have heard that, if I take the vaccination, my situation may get worse”*** (male, 41 y.o., severe mobility and cognitive disabilities).

This self-perception of vulnerability was also tied to the limited access to quality health care: ***“I believe that if you have a disability, you may have high risk compared with others in getting the disease and you will not find good care”*** (male, 64 y.o., mobility disability); ***“I am more at risk than others due to lack of access to health services and stigma from the community”*** (female, 36 y.o., severe hearing and communication disabilities).

Social Processes and Norms

Family norms

For the reasons exposed above, this study also explored the role of family norms and autonomy in health decision-making. Indeed, the latter was often influenced by family, especially when the latter were caregivers: ***“I always share the decision with my relatives, because they support me when I am sick”*** (male, 42 y.o., mobility disability); ***“My family will never agree to me taking the vaccine, they don’t want to harm me more”*** (male, 20 y.o., severe communication and self-care disabilities). In one case, this evaluation of the risks of side effects was internalized and, paradoxically, the principle of precaution consisted in not seeking prevention: ***“If I develop complications, it will be a double burden for them”*** (male, 40 y.o., multiple disabilities).

Gender equity - autonomy

As expected, gender was also a major factor in health decision-making among persons with disabilities: ***“I would not do what my husband does not agree with”*** (female, 36 y.o., severe hearing and communication disabilities); ***“I have to ask the permission of my husband to take the COVID-19 vaccine”*** (female, 63 y.o., mobility disability); ***“I have to consult with my husband first”*** (female, 35 y.o., hearing disability).

Religious leaders

When exploring how opinions are influenced by religion and religious leaders, we should also consider the specific perspectives of persons with disabilities. While religious authorities supported immunisation overall, Persons with disabilities were less likely to have access to this source of information: ***“I don’t know what religious leaders say, I don’t go out often”*** (female, 60 y.o., mobility and hearing disabilities). Access to this kind of information was also shaped by gender: ***“I am a female, I do not engage with community leaders and males, so I do not know what they would recommend”*** (female, 36 y.o., severe hearing and communication disabilities).

Religious beliefs

Apparently, religious beliefs often resulted in a form of fatalism and resignation: **“Whatever God has planned for us will happen”** (female, 60 y.o., mobility disability); **“I have no concerns, I believe in God. Nothing will happen to me unless it’s written for me”** (female, 46 y.o., mobility and visual disabilities). One participant explicitly transposed these beliefs to vaccination: **“I don’t think a man-made product will prevent me from getting a disease”** (female, 34 y.o., mobility and self-care disabilities).

Motivation

Vaccinated respondents

Out of the 30 persons with disabilities interviewed, 10 respondents were already vaccinated against COVID-19. Among them, health concerns were considered very relevant: **“I have chosen to receive the COVID-19 vaccine because I am an elderly person and I have diabetes”** (female, 54 y.o., severe mobility disability). Few of them expressed enthusiasm in convincing others to get vaccines, acting as informal champions of sorts of vaccination by showing that persons with disabilities could actively participate in immunisation campaigns if the opportunity arose: **“I’m a teacher and I was one of the first to take it in my area and once my community saw me take it or heard it, then they followed me and took the vaccine”** (male, 54 y.o., mobility disability).

Motivated respondents

Twelve participants showed a clear motivation to get vaccinated after seeing other doing so: **“I have seen people who took it and [they were] fine so yes, I am ready to get it”** (female, 29 y.o., mobility disability); **“Now we see a lot of people who’ve been vaccinated, my family and friends will take it too”** (female, 50 y.o., multiple disabilities). However, some of these motivated people still met too many barriers curtailing their intention: **“I will take the vaccine if I know where to find the vaccine”** (female, 60 y.o., mobility and visual disabilities); **“My family will take it if they know where there is vaccination”** (female, 23 y.o., cognitive and visual disabilities).

Reluctant respondents

Eight participants had decided not to get vaccinated, with some clearly being against this option: **“I don’t like taking vaccination, I don’t want to risk my health”** (female, 34 y.o., mobility and self-care disabilities); **“No, I don’t want any treatment of COVID-19 vaccines because I believe that this vaccine is made from pork”** (female, 63 y.o., mobility disability).

Practical Issues

Basic needs

The first practical issue that emerged from persons with disabilities' testimonies was the urgency of their basic needs, demonstrating once more that vaccination and health prevention cannot be separated from the other SDHs, especially among Persons with disabilities: ***“In my neighbourhood, we don't discuss about disease and treatments, we are already struggling with our daily life. We don't have what we will eat tomorrow, so, coronavirus is not a concern to us”*** (female, 60 y.o., mobility and visual disabilities); ***“I recently came to the camp, I am a new refugee here, I am from a rural area, we were nomads, we had livestock, but when the drought happened I lost everything”*** (male, 45 y.o., cognitive and communication disabilities).

Knowing where to get vaccines and information

As for sources of information, the radio seemed to be the device used the most often: ***“I own a radio and always listen to Radio Hargeisa, which is where the government broadcasts information regarding the COVID-19 vaccine”*** (male, 58 y.o., mobility disability). However, these messages could be contradicted by the community members whose source of information was the Web: ***“When you go out and meet people, those who use the Internet, they tell you that vaccines are bad. I am old, I don't know how to use the Internet”*** (male, 54 y.o., hearing and self-care disabilities). In addition, Persons with disabilities did not always have access to the same channels or opportunities to receive correct information in a timely manner during a health emergency: ***“I don't know how to get the COVID-19 vaccine, I lack information because of my disabilities: I cannot go to the place where information is given and no one comes to inform me about these matters”*** (female, 60 y.o., mobility and visual disabilities). Another participant confirmed how disability, gender, and coming from rural areas may interact in shaping access to information: ***“I came recently and don't know anything about the COVID-19 vaccine and I also don't have enough information about taking care of my health. I don't know where to go. It's related to my disability because I don't go anywhere, most of the time I stay at home”*** (male, 40 y.o., multiple disabilities).

Regardless of the source of information, Persons with disabilities may meet specific barriers as a result of their disabilities: ***“I am among the persons with disabilities: it is especially difficult for me to hear new things”*** (female, 35 y.o., hearing disability). Even when information was provided at the household level by outreach teams, their lack of inclusivity skills made their efforts unsuccessful in many cases: ***“I didn't understand what the team was saying at the beginning because they didn't know how to speak with me. [...] I only understood when my mother translated to me”*** (female, 36 y.o., severe hearing and communication disabilities).

Affordability

Even if the vaccines were free, the policy of only distributing them in a few centres would still make transportation an issue in terms of costs and logistical arrangements: ***“I don’t know if it’s money to get the vaccine, but I have to pay for transportation”*** (female, 50 y.o., multiple disabilities); ***“I don’t have someone who will look after my kids, my mom is old and bedridden and she cannot look after my kids; I also have a vegetable shop. Who is going to look after it if I go for vaccination?”*** (female, 34 y.o., mobility and self-care disabilities). A lack of support for isolated Persons with disabilities within the community may also limit their access to health care regardless of their health needs or intentions: ***“I can’t go anywhere because of my limitation. I don’t have any children to look after me, it’s only me. My neighbours help me a lot, they look after me, they provide food for me, so, I can’t add that to them asking to take me to places like hospitals”*** (female, 60 y.o., visual disability).

Moreover, past experiences with the health system and related costs (***“Since we are nomads, I have never seen a place where vaccines are provided for free”*** – female, 53 y.o., mobility and visual disabilities) may discourage respondents from seeking non-urgent health care: ***“Every time you go, they tell you to take a new test which is money”*** (male, 41 y.o., severe mobility and cognitive disabilities). This may have dramatic results: ***“I’m sick and I can’t afford to go to the hospital”*** (female, 60 y.o., visual disability). Even emergency care may cause financial hardships: ***“I have lost my arms and my eyesight because of the explosion. [...] It was a painful experience. The doctors were very busy, there were a lot of injured people. They tried what they could and they saved my life. [...] [But] we didn’t have enough money, we couldn’t pay for the treatment, and my relatives borrowed money”*** (male, 54 y.o., hearing and self-care disabilities).

Interestingly, because of financial barriers, some respondents sought support and care in local pharmacies: ***“I haven’t seen a doctor before, only that pharmacy where I get some medicine”*** (female, 60 y.o., visual disability); ***“I prefer going to the pharmacy as soon as I feel unwell”*** (female, 53 y.o., mobility and visual disabilities); ***“I go to nearby pharmacies, it’s cheaper and they are my neighbours”*** (female, 34 y.o., mobility and self-care disabilities).

Past experiences with health services and personnel

Persons with disabilities can further experience health services in a passive way when there is a lack of opportunities for inclusive and meaningful participation: ***“Individuals with disabilities tend to follow their doctors’ orders without having strong opinions regarding the COVID-19 vaccine. We are told this is good for you and we take it; no one asks us our opinion; if we refuse something, we might not get the opportunity later”*** (male, 41 y.o., severe mobility and cognitive disabilities).

Negative past interactions with health staff in the context of vaccination or other health services also seem to be a powerful driver shaping trust: ***“I don’t trust the health care worker that provides the vaccines because of poor communication: they treat you like small children, they don’t respect you”*** (female, 63 y.o., mobility disability). This is confirmed by other testimonies: ***“Once, I was sick and I went to the hospital. The clinic was very busy. The lady who was working for me had a lot of clients, so often she would tell me to hurry up. I felt like I was a burden. [...] For that reason, I do not go to clinics that much”*** (female, 23 y.o., cognitive and visual disabilities). Persons with communication disabilities may further find general services not to be adapted: ***“I was lost, I did not understand what was going on because there were a lot of people gathered. The place was overcrowded and I did not have someone to tell me how to proceed or where to start”*** (female, 36 y.o., severe hearing and communication disabilities).

As requested by participants, facilitating access to the vaccination sites could be a winning strategy: ***“I want a vaccine that is accessible and available in my neighbourhood or some people who can guide me and walk with me”*** (female, 53 y.o., mobility and visual disabilities). Among positive experiences, this one is worth noting: ***“The vaccine was brought to my doorstep, and I didn’t have to travel for it. I didn’t have to go to anyone else’s house nor queue up somewhere for it. They knocked on my door and asked if needed a vaccine and I said yes”*** (female, 40 y.o., severe self-care disability).



“I am diabetic and my leg has been amputated for that reason; I also lost most of my eyesight because of it. I was born with diabetes. My parents didn’t believe in doctors’ treatment and also they couldn’t afford the treatment, so I have to face the consequences now” (male, 33 y.o., severe visual disability).

Interviews of Health workers

“There is one group that is always not reached and they are the disabled people, they are not always included. They don’t come to the health facilities. I encourage you to find ways we can actually make them come to the centres.”

(EPI, female, 30 y.o.)

All the health workers interviewed reported that persons with disabilities did not attend health services regularly: *“You see one person who is disabled once in a while”* (nurse, female, 38 y.o.); *“There may be months where we don’t see them at all”* (doctor, male, 33 y.o.). This lack of interaction contributed to health workers’ unease dealing with them: *“We haven’t had much experience interacting with persons with disabilities and we are unsure about how to accommodate their needs”* (nurse, male, 46 y.o.).

Among the barriers accounting for the low COVID-19 immunisation rates, health workers pointed out product availability as a major issue: *“We don’t have the vaccine here anymore, we refer them to the hospital. Corona vaccination isn’t available like other vaccines. Vaccination was available at our hospital before, but not now”* (public health officer, female, 45 y.o.).

However, availability is a prerequisite: *“Only a small number of clinics has it, so I will recommend making it available for every district. You can’t tell an elderly person who came to you: I don’t have it, go to another place”* (nurse, female, 38 y.o.). The first to suffer from this lack are marginalised areas and populations: *“There are areas where the vaccines did not reach and those people also need it”* (EPI, female, 53 y.o.). Thus, a nurse concluded the following: *“We need to plan how we can make vaccination accessible for everyone: this disease can return at any moment, we cannot go back to how we were in 2020”* (EPI, female, 53 y.o.).

However, outreach programmes are not always a solution either: *“One time I went to a camp for work, I was providing vaccination, a lot of disabled people came to me, they were asking if we give the vaccine to people like them”* (nurse, female, 32 y.o.); *“Sometimes, we also do outreach programmes to the camps: sometimes, a person will come to you and tell you they have a sick disabled person and they want treatment for them. When you say, ‘bring the person [to the health centre],’ they will say they can’t”* (nurse, female, 48 y.o.).

Overall, health staff confirmed what we discovered listening to persons with disabilities. First, a misunderstood link between disability and health: ***“They think the vaccine will cause them harm or exacerbate their current condition”*** (EPI, female, 25 y.o.); ***“They may be told if you get the vaccine, things will get worse for you”*** (doctor, male, 33 y.o.). Second, the role of intersectionality: ***“A lot of residents of the camp are from rural areas, they do not know where to look for health care”*** (nurse, female, 35 y.o.); ***“The older people with disability don’t like taking any kind of drugs”*** (EPI, female, 25 y.o.).

The health workforce also confirmed that when it is the caregiver who decides, barriers are set by the social norms operating in the family circle around the PwD: ***“People prioritize the normal person over the disabled person. For example, a mother has two children, one has a disability and the other one does not. She will put all her effort into raising the normal child, she can think that she may benefit from this normal person: he is going to work for the family when he grows up. On the contrary, the disabled child could suffer health issues. So, she will give more care to the normal child”*** (nurse, female, 38 y.o.).

Furthermore, they also highlighted the role of structural barriers and discrimination: ***“Society discriminates against persons with disabilities, so the person loses confidence in reaching out for help”*** (nurse, male, 27 y.o.). Another participant clearly stated: ***“One reason is that society has made them feel like they are not important and they are not the same as others”*** (IYCF nurse, female, 24 y.o.). Therefore, ***“[t]heir problem is not only getting health care service, but also not being able to be part of the community”*** (nurse, female, 35 y.o.).

Despite this stark picture, health professionals’ sectorial perspective offers powerful insights about Inclusive Health. First, they underlined their own lack of training. They did not always feel well-trained and able to deal properly with persons with disabilities seeking health services: ***“This is stressful, I don’t know if I have treated them right or not. I don’t feel comfortable while working with them”*** (nurse, female, 35 y.o.); or, in a concrete example: ***“I had a mother who was pregnant who visited me; she had lost both legs. I wanted her to sit on the examination bed and I didn’t know what to do. In the end, we discussed and she was comfortable sitting on a chair and then climbing onto the bed. We are not trained on how to take care of these people, whether while you are studying or at work”*** (nurse, female, 32 y.o.). Inclusive Health training could therefore be a game changer: ***“Before, I didn’t know and also didn’t think about them, then I participated in training you [HI] were carrying and it opened my eyes, I realized we have been missing part of the population”*** (nurse, male, 27 y.o.).

This lack of Inclusive Health has real dramatic effects on health outcomes and quality of care. Without proper health staff training, even those who do attend health services may suffer from poor treatment and might not come back even when they need it, as shown by this anecdote: ***“I remember there was this pregnant lady who was deaf and couldn’t talk. She***

came to the hospital bleeding and she was in labour. Her family said she was not married and they didn't want her. On the other hand, the health care workers on duty suspected her of having HIV. So, they said that the operation room was not functioning and they referred her to another hospital" (IYCF nurse, female, 24 y.o.).

Interestingly, at the systemic level, few health workers mentioned the importance of collecting disaggregated data, a pillar of inclusive health systems: ***"We don't document them in our register; maybe if we did, we could realize how often we see them [persons with disabilities]"*** (EPI, female, 26 y.o.); ***"We have to add them to our reporting system"*** (nurse, female, 32 y.o.).



"One of my current patients is a child whose mother is a disabled person, she doesn't have her legs so she can't walk. A Bajaj brings her to the health facility, but she also has difficulty entering the centre. I tell her to call me when she arrives. [...] The reason I am doing so is for her to come back whenever she has a health problem" (OTP nurse, female, 25 y.o.).

All in all, making changes toward more disability-inclusive care is possible: ***"We, as health care workers, have not done a very good job in that area. If we had done more outreach and awareness, something would have changed; but we still have time"*** (nurse, female, 48 y.o.).

In terms of practical recommendations, the health workers interviewed shared powerful inputs for inclusive health services and vaccination: ***"Most of the disabled persons I see have a health problem. They need to be put at the centre of what we are doing. [...] We need to go get them at their places, we don't have to wait for them to come"*** (nurse, female, 32 y.o.).

Part 4 – Recommendations

The following recommendations emerged from the analysis of the quantitative and qualitative data—thus, from the voices of Persons with disabilities sharing their unique experiences accessing health care in a fragile context—as well as from the reflections of the HI team involved in the study and engaged for the right to health.

4.1 Recommendations for immunisation campaigns that leave no one behind

- Vaccination should be available as closely as possible to vulnerable areas and communities (for instance, at the primary health care level in accordance with the Alma-Ata Declaration). This study did not assess infrastructures for cold chain and medical product storage nor the health workforce’s competencies in administering vaccines. Nevertheless, the current COVID-19 vaccination setup limits access for those who encounter practical issues and barriers.
- Vertical immunisation programmes for specific diseases like COVID-19 should be integrated into the overall offer of basic health services. Persons with disabilities, especially those coming from rural areas, have had scarce access to health information and services so far. Therefore, we strongly suggest coupling vaccination with general medical services, with the double aim of delivering vaccination and increasing the early detection of any other health issue for those persons who have never or hardly ever met a nurse or a doctor.
- Applying the BeSD tools among specific vulnerable populations is a useful strategy for identifying the key barriers at play in a given context. The outputs of the BeSD inquiry should therefore be used to design a realistic theory of change for RCCE plans and activities. Considering how fundamental this inquiry phase is to making RCCE adaptive and effective, as demonstrated by this study, we call for health programme donors to allocate sufficient time and funds to applied research before scaling up prevention actions.

4.2 Recommendations for a disability-inclusive use of the BeSD tools

- The WGQ should be integrated into the socio-demographic data in order to allow disaggregated data analysis by age, gender, and disability. In this way, it is possible to gain a deeper understanding of the collected data, revealing hidden inequities (barriers are neither the same for everyone nor experienced in the same way).
- A major driver of promoting an inclusive use of the BeSD tools is undoubtedly giving data collectors proper training, both for the quantitative and qualitative parts. This

training should explore the staff's attitudes toward disabilities, explain the DCP, offer practical tips for communicating with persons with diverse and/or multiple disabilities, and highlight what meaningful participation entails in practice. Involving OPDs in this training and in other phases of the BeSD framework presents great added value.

- As we have seen, some Persons with disabilities may need reasonable accommodation when involved in data collection. Once the target sample's needs are identified, these measures should be planned in advance in terms of resources like visual supports, sign language translators, etc. or of time allocated by the team to active listening.

4.3 Recommendations for Disability-Inclusive Health in the health systems

- A single programme or tool can be inclusive if the whole health system is growing increasingly inclusive in line with international standards, the WHA resolution on the highest attainable standard of health for persons with disabilities, and the CRPD. The first step is promoting capacity-building on Inclusive Health and Health Equity for the health workforce. Moreover, inclusive health system better serves the general population as well.
- As mentioned above regarding the BeSD tools, disaggregated health data by age, gender, and disability are the key to decoding inequities. To this date, there are no systematic data about the impacts of COVID-19 and about COVID-19 vaccination among persons with disabilities (i.e., 1.3 billion people worldwide, thus 16% of the world population).
- Considering the Health in All Policies (HiAP) approach, an effective EID prevention strategy includes working on the SDHs and social inclusion. This would strengthen social protection and informal support networks to help persons with disabilities address and overcome barriers along the pathways to health care.

Part 5 – Conclusions

This work was born from a collaboration between WHO and the Humanity & Inclusion INGO, being it in formal relationship with WHO. This close collaboration could be considered a good practice: as a health actor on the field, HI applied preexisting validated tools (the BeSD); conversely, through its field experience and expertise working in hard-to-reach areas (HRAs), HI may contribute to improving these tools.

Our experience confirmed the usefulness of the BeSD manual, which offers a clear framework, a logical methodology, and practical tools to guide the implementation of inquiries and assessments.

If we still needed it, we also obtained the confirmation that the struggle against COVID-19 has not ended even though WHO does not consider it a Public Health Emergency of International Concern (PHEIC) anymore. Even now, over three years after the declaration of the pandemic, the most vulnerable populations in fragile settings are still a blind spot of the global efforts against SARS-CoV-2.

Therefore, addressing issues like vaccination, the infodemic, and access to health information and services for all are crucial steps, both in terms of Health Equity and of preparedness to the next outbreak.

It further clearly appeared that past experiences with health services and staff are a major driver shaping help-seeking behaviours and trust. This study thus calls for a systematic, intentional effort toward strengthening health systems at all levels, leaving no one behind.

The data also showed, among other enablers and barriers, that the financial hardships of accessing health care or using transportation to the health centres are a huge challenge that needs to be tackled to achieve the Universal Health Coverage 2030 agenda.

Finally, this study clearly shows that intersectionality matters. Age, gender, disability, and IDP status shape each person's experience, decisions, and capabilities in attaining the highest standard of health.

Appendixes

1. BeSD priority questions and indicators

Domain/ construct	Childhood vaccination survey		COVID-19 vaccination survey	
	Priority question	Priority indicator	Priority question	Priority indicator
Thinking and feeling Confidence in vaccine benefits	How important do you think vaccines are for your child's health? Would you say... <input type="checkbox"/> Not at all important <input type="checkbox"/> A little important <input type="checkbox"/> Moderately important, <i>or</i> <input type="checkbox"/> Very important?	% of parents/caregivers who say that vaccines are "moderately" or "very" important for their child's health	How important do you think getting a COVID-19 vaccine will be for your health? Would you say... <input type="checkbox"/> Not at all important <input type="checkbox"/> A little important <input type="checkbox"/> Moderately important, <i>or</i> <input type="checkbox"/> Very important?	% of adults/health workers who say a COVID-19 vaccine is "moderately" or "very" important for their health
Social processes Family norms	Do you think most of your close family and friends want you to get your child vaccinated? <input type="checkbox"/> NO <input type="checkbox"/> YES	% of parents/caregivers who say most of their close family and friends want their child to be vaccinated	Do you think most of your close family and friends want you to get a COVID-19 vaccine? <input type="checkbox"/> NO <input type="checkbox"/> YES	% of adults/health workers who say most of their close family and friends want them to get a COVID-19 vaccine

Domain/ construct	Childhood vaccination survey		COVID-19 vaccination survey	
	Priority question	Priority indicator	Priority question	Priority indicator
Motivation Intention to get vaccine	[COUNTRY NAME] has a schedule of recommended vaccines for children. Do you want your child to get none of these vaccines, some of these vaccines or all of these vaccines? <input type="checkbox"/> NONE <input type="checkbox"/> SOME <input type="checkbox"/> ALL	% of parents/caregivers who say they want their child to get "all" of the recommended vaccines	Do you want to get a COVID-19 vaccine? Would you say... <input type="checkbox"/> You do not want to, <input type="checkbox"/> You are not sure, <input type="checkbox"/> You want to, <i>or</i> <input type="checkbox"/> You are already vaccinated?	% of adults/health workers who say they want to get a COVID-19 vaccine
Practical issues Know where to get vaccination	Do you know where to go to get your child vaccinated? <input type="checkbox"/> NO <input type="checkbox"/> YES	% of parents/caregivers who say they know where to get their child vaccinated	Do you know where to go to get a COVID-19 vaccine for yourself? <input type="checkbox"/> NO <input type="checkbox"/> YES	% of adults/health workers who say they know where to get a COVID-19 vaccine for themselves
Practical issues Affordability	How easy is it to pay for vaccination? When you think about the cost, please consider any payments to the clinic, the cost of getting there, plus the cost of taking time away from work. Would you say... <input type="checkbox"/> Not at all easy <input type="checkbox"/> A little easy <input type="checkbox"/> Moderately easy, <i>or</i> <input type="checkbox"/> Very easy?	% of parents/caregivers who say vaccination is "moderately" or "very" easy to pay for	How easy is it to pay for vaccination? When you think about the cost, please consider any payments to the clinic, the cost of getting there, plus the cost of taking time away from work. Would you say... <input type="checkbox"/> Not at all easy <input type="checkbox"/> A little easy <input type="checkbox"/> Moderately easy, <i>or</i> <input type="checkbox"/> Very easy?	% of adults/health workers who say vaccination is "moderately" or "very" easy to pay

Full version available here: <https://apps.who.int/iris/handle/10665/354459>

2. Washington Group short set (WG-SS)

VISION

[Do/Does] [you/he/she] have difficulty seeing, even if wearing glasses?

Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

HEARING

[Do/Does] [you/he/she] have difficulty hearing, even if using a hearing aid(s)?

Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

MOBILITY

[Do/Does] [you/he/she] have difficulty walking or climbing steps?

Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

COGNITION (REMEMBERING)

[Do/does] [you/he/she] have difficulty remembering or concentrating?

Would you say... [*Read response categories*]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

SELF-CARE

[Do/does] [you/he/she] have difficulty with self-care, such as washing all over or dressing?

Would you say... *[Read response categories]*

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

COMMUNICATION

Using [your/his/her] usual language, [do/does] [you/he/she] have difficulty communicating, for example understanding or being understood?

Would you say... *[Read response categories]*

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

Full version and instructions available here: <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>

3. Extra questions for the interviews of health workers

- 1) Do persons with disabilities come to the centre regularly to receive health care? Why (or why not), in your opinion?
- 2) Do persons with disabilities come to the centre to get vaccinated against COVID-19? Why (or why not), in your opinion?
- 3) How comfortable do you feel with addressing persons with disabilities' communication and health needs?



Prevention against Emerging Infectious Diseases: An opportunity for Inclusive Health

Understanding the behavioural and social drivers (BeSD) of COVID-19 vaccination among persons with disabilities in Internally Displaced camps in Somalia/Somaliland

This document presents the results of a quantitative and qualitative study carried out by the local HI team among persons with disabilities in IDP camps in Somalia/Somaliland in 2023.

Using WHO's BeSD framework, this study identified their drivers and barriers to accessing COVID-19 vaccines.

This experience contributes to making the use of these tools more inclusive.

Based on the results of this study, HI calls for Inclusive Health in the health prevention.

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