Towards Truly Universal Access

Barriers to accessing health services for people with disabilities in Northwest Syria

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SAMS

This report was prepared with assistance from Mr.Alaa Zaza.
SAMS is fully responsible for the content of this report.

SAMS

Syrian American Medical Society

About SAMS

The Syrian American Medical Society (SAMS) was founded in 1998 as a professional society to provide networking and educational opportunities to medical professionals of Syrian descent across the United States. The charitable arm of SAMS, SAMS Foundation, was launched in 2007. With the eruption of the conflict in Syria, SAMS Foundation has become one of the most active medical relief organizations working on the front lines of crisis relief in Syria, neighboring countries, and beyond.

Our Mission

is dedicated to delivering life-saving services, revitalizing health systems during crisis, and promoting medical education via a network of humanitarians in Syria, the US, and beyond.

Our Vision

is to strengthen the future of Syria's healthcare, delivering dignified medical relief where needed, fortified by a dedicated medical community.

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Executive summary

Introduction

The Syrian American Medical Society (SAMS) conducted a study to better understand the barriers to accessing healthcare services for people with disabilities in Northwest Syria. Barriers, in this regard, were classified into financial, structural, communication, and attitudinal barriers. In addition to improving understanding of barriers to accessing services, the study also aimed to examine the prevalence of disability among SAMS' beneficiaries and workers and understand coping mechanisms by the affected population and their recommendations.

The research answered the following questions:

RQ#1 What is the prevalence of disability in NW S?

RQ#2 What are the most reported barriers to access health services for people with disabilities in Northwest Syria?

RQ#3: What are some of the key recommendations to provide disability-inclusive services?

Key findings and recommendations

Overall, it was demonstrated that prevalence of disability among beneficiaries of SAMS' health services were 15.5% for adults. This is comparable to global research (15%-15.8%) on disability prevalence. No significant difference was found between male and female beneficiaries.

The top-level findings of this research are as follows:

- **Transportation** was found to be the top structural barrier to access both specialized and general healthcare for people with disability. No significant difference was found between specialized and general services.
- **Cost** of transportation, cost of medicines (particularly for chronic and rare diseases) and cost for certain tertiary diagnostic and treatment services were the top financial barriers for people with disabilities.
- **Barriers** increase as the level of healthcare services increases. Patients with disabilities requiring secondary or tertiary services face more barriers as compared to those requiring primary health services.
- **No** statistically significant difference was found between the attitudes of people with disabilities toward specialized and general healthcare services, which indicates similar barriers to access in both types of services.
- **Information** about available and free services was found to be one of the top communication barriers. The way information is presented to people with disabilities lacks accommodations to their specific needs.
- **Attitudes** of healthcare workers in both specialized and general healthcare services were found to be positive and do not present a barrier for people with disabilities. However, no evidence of adaptations in the provision of care to accommodate for the

needs of people with disabilities.

- **No** significant difference was found in the attitudes of female and male patients towards healthcare services. They both shared the perception of facing the same barriers.

The top-level recommendations of this research are as follows:

Healthcare providers recommendations:

Transportation: Provide transportation support and explore options such as linkages with civil defense, and health ambulances network, cash assistance and protection services and strengthening referral pathways.

All in one: Consider combining or integrating specialized healthcare services with general services. Offering all services in one place might reduce travel and its cost and ensure patients have access to multiple services.
Revisit appointment systems and information sharing practices to include accommodations for people with disabilities.

Last resort: Advocate and coordinate with other actors to improve the provision of tertiary services or have dedicated task forces to act as last resort for rare and chronic conditions particularly those with low supply (For example, neurologists).

Universal design: Prioritize universal design adaptations to improve accessibility of people with disabilities oto the healthcare facilities with a particular focus on transportation and triage/reception/waiting rooms.

Donors recommendations:

Reduce policy barriers related to include transportation costs as eligible costs for multiple sectors to reduce the barrier of transportation.

Explore with the donor community and development partners a wide scale solution to the supply of public transportation. That is also adapted for disabled persons

Enforce universal design practices to healthcare projects with a focus on low cost and wide scale adaptations. Prioritize information sharing and physical accessibility.

Coordinate with other donors and development partners to develop a longer-term healthcare inclusion strategy that focuses on systems strengthening and cross sectoral collaboration.

Strengthen the inclusion of disabled people organisations and affected people with disabilities from the local communities in the coordination and decision-making processes.

Researchers recommendations:

Use of behaviour change communication to promote universal design practices within the healthcare systems.

Investigate barriers and facilitators for people with disabilities and their households to have employment and opportunities to generate income.

Equity research to highlight the voice and needs of people with disabilities and provide evidence to address specific donors’ policy barriers and negative value for money perceptions.

1. Literature review and background

1.1 DEFINING DISABILITY

Approximately one billion people live with disabilities worldwide [1]. Two models defining disability are often used: the medical model and the social model. The medical model views a disability as a condition that impairs an individual from living a normal and full life and needs an intervention or treatment. The social model views impairment and disability separately. According to this model impairment is an injury, illness, or congenital condition that causes a loss or difference of physiological or psychological function, whereas disability is a social construct. A disability is the interaction of the impairment with the environment. The way that society is organized, not the impairment itself, excludes people with disability from full participation in society.

For this research, we will be using the international classification of functioning, disability, and health (ICF). The WHO's International Classification of Functioning, Disability and Health (ICF) is based on the idea that impairments can cause problems with a person's functioning, and that barriers in the environment can mean that functional limitations restrict a person's activities and participation in their community.

Defining Disability

Disability is a result of an interaction between a person with an impairment and the attitudinal and environmental barriers around them. Disability should not only be measured by a diagnosis of the underlying health, learning, psychological, neurological, or emotional condition, but should also consider environmental factors that might impact access and participation. The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) is the globally accepted way of defining and measuring disability. The World Report on Disability provides a clear description of the various constructs which make up the ICF. Disability arises from the interaction of health, learning, psychological, neurological, or emotional conditions with contextual factors – environmental and personal, and is considered as being difficulties encountered in any or all three areas of human functioning:

1. Impairments are problems in body function or alterations in body structure, such as, paralysis or blindness.
2. Activity limitations are difficulties in doing activities such as walking or eating.
3. Participation restrictions are problems with involvement in any area of life - for example, facing discrimination in employment or transportation.

1.2 IMPACT OF THE CRISIS

In March 2011, peaceful demonstrations across many Syrian cities were faced with a harsh response. The situation escalated, and by 2012, the International Committee of the Red Cross declared that Syria was in a state of civil war. [2] Since then, the conflict has evolved to a multiple, parallel, non-international and international armed conflicts [3]. This violence became the leading cause of death and conflict-related disability for Syrians and was described as one of the worst human-made disasters the world has seen since World War II [4]. In 2022, the conflict entered its eleventh year.

The UN Office of the High Commissioner for Human Rights estimates that 306,887 civilians were killed between March 1st, 2011 and March 31st, 2021 in Syria due to the conflict [5]. This appears to be a conservative estimate, compared to other sources that estimated at least 500,000 dead by 2018 [6]. Furthermore, approximately three million Syrians have been injured, and almost half of them have permanent disabilities, including 86,000 amputations [7]. Estimates regarding death resulting from the war and conflict-related disability vary, and little research has been done to give more accurate estimates. According to the World Health Organization in 2016, 30,000 people each month were estimated to be injured by the Syrian conflict, many of whom will suffer lifelong disabilities. 30% of trauma cases are estimated to result in permanent disabilities requiring long-term rehabilitative care [8].

In research published in 2022, a total of 14.9% of households reported having at least one person with a Severe Violence Related Disability (SVRD) (disability that is more than minor and interfered with the victim’s daily tasks), of whom 17.1% were women and 82.9% men. The main type of SVRD was physical limb deformities resulting in movement impairment, followed by physical or cognitive limitations due to neurotrauma, and paralysis due to spinal cord trauma. [11] A more recent UN study found that nearly a third (30%) of Syrians aged 12 and up have disabilities – double the global average of 15%. In the same study, over a third (37%) of Internally Displaced Persons (IDPs) aged 12 and up, and 40% of heads of households, have disabilities. [12] Health services during conflicts face very challenging obligations, injuries resulting from the crisis always take the priority linked with its great demand leaving fewer resources for people with disabilities that are not caused by hostilities. [13]

In 2018, a survey was done among people with disabilities in Syria, where over 60% stated that their disability condition has been exacerbated by the crisis. Common reasons highlighted included the lack of accessibility to health centers and inability to meet their basic needs. [14]

Attacks on civilians and healthcare facilities, combined with overwhelming psychological and socio-economic consequences have complicated the situation for people with disabilities. High inflation rates, currency depreciation, unemployment, destruction of property and loss of assets, devastated health infrastructures and repetitive, mass displacements have contributed to the disruption of people with disabilities’ ability to access health services they desperately need.

Disability and accessing healthcare

1.3 AVAILABILITY AND ACCESSIBILITY

It has been said that “while health is not everything, everything is nothing without health.” [15]. Good health is the limiting factor for participation of people with disabilities in all aspects of life, including education, work, and social relationships. Around the world, people with disabilities experience challenges in access to healthcare services. They also experience higher rates of poverty, which in turn force them to face conditions that impact their health in a negative way, including lack of access to water and sanitation, food security, and livelihood opportunities, among others. Some persons with disabilities are more susceptible than the general population to secondary health conditions due to their disability and living conditions. Therefore, they may have greater health needs than the general population.

In times of emergencies, this is further exacerbated, and many people with disabilities are further marginalized and excluded, experiencing an inability to access basic services, obtain information in an accessible format and receive medicines or medical interventions.

As of September 2021, out of the almost 1,800 available public health centers, 45% were not fully functioning [16]. The health sector in Syria lacks the capacity to provide comprehensive services for trauma and rehabilitation following surgeries across the country.[17]

Attacks on health facilities led to substantial damage to health facilities or the areas around them, further limiting accessibility. Out of more than 1,380 reported attacks, Physicians for Human Rights (PHR) has documented and verified 601 attacks on at least 350 health facilities since the start of the conflict. [18] Those attacks continued to rise, reaching 1077 unique incidents in 2021. Attacks on health cause death, injuries, and terror among civilians. [19]

People most at risk include people living with chronic diseases and/or disabilities, those in need for mental health and psychosocial support, and survivors of trauma, including those who sustain a disability because of the conflict. WHO estimates that one in five Syrians has moderate mental health issues, and 1 in 30 is at risk of developing severe or acute mental health needs. [20] The ongoing bombardment is the primary cause of children’s daily psychological stress. Consequently, 1 in 4 children are at risk of severe mental health disorders – with potentially lifelong consequences. [21]

Without proper inclusion efforts, people with disabilities often face barriers to health services in relation to both the supply of health services by health workers, facilities, and the demand for and uptake of health services by people with disabilities and their families.

An estimated 3.46 million people with disability are more likely to be excluded, and households affected by disability were most likely to report living more than 1 hour from a health facility, struggling with barriers including paying for health care, non-availability of needed services, fear of COVID-19 at the health facility, and lack of access at the health facility for persons with disability or mobility challenges. [22]

Financial, psychological, informational, social, cultural, geographic and temporal factors also influence the way people access and utilize the healthcare system. One of the key contributors to psychosocial distress among persons with disabilities is the inability to find work and the related dependency on family savings [23]. Similarly, inability to find work and income reduces their chances to access healthcare. For example, only 62% of households with at least one member with disabilities have access to health services, as compared to 67 percent of households without a member with disabilities. This disparity suggests that while both household types might have a similar distance from the health facility, dependency on healthcare services may affect household income and mobility, which in turn negatively affects access for households most dependent on health services. Indeed, households with members with disabilities spend an average of 38 percent more on health care and 28 percent more on fuel monthly compared to households with no members with disabilities. [24]

Why women and girls with disabilities are some of the most vulnerable Syrians.

"Having a disability in Syria often means that you are hidden away. You confront shame, discrimination, and physical barriers. You are pitied." Nujeen Musatafa, a young woman living with Cerebral Palsy told the UN in 2019. She said that people like her are "invisible" in conflicts. [25]. Although prevalence rates of disability in Syria indicate men are only slightly more likely to have a disability (28%) than women (25%), [26] women with disabilities have specific vulnerabilities that should be understood.

Women and girls with a disability are disproportionately more likely to experience gender-based violence than women that do not have a disability [27]. Further, women and girls who are displaced or have a disability, can be exposed to higher levels of risk overall and face specific forms of sexual violence as well. For instance, according to the Women's Refugee Commission's report on global disability inclusion, women and girls with disabilities are most likely to experience instances of sexual violence, while men and boys with disabilities are more likely to suffer increased physical or psychological harassment. [28]

To access medical care in response to gender-based violence, a woman with a disability is more likely to face compound social stigma and other barriers faced by survivors of GBV compared to survivors without a disability.

Access to livelihood and availability of sustainable income are closely linked to women's ability to access healthcare. Unfortunately, only 7% of women with disabilities are currently engaged in the labor force, compared to 62% of men with disabilities. [29] Fewer than 30% of women without a disability and only about 12% of those with a disability are employed, compared with 85% of men without a disability and 74% of men with disabilities [30]. Other studies indicate that poverty and unemployment rates are significantly higher in female-headed households [31] which has a detrimental impact on the household of a person with disability in need of healthcare.
Furthermore, women with a disability are almost 6 times more likely to be widowed than women without a disability. [32] This is significant, as persons with disabilities are often more reliant on increased spousal or next-of-kin dependence, than those without disabilities.

The above staggering figures demonstrate that women and girls with disabilities are some of the most vulnerable in the Syrian crisis.

The above factors related specifically to accessibility to healthcare were not investigated in the context of northwest Syria. Very limited research was found to investigate the interactions of people with disability and these barriers and ways to overcome or cope with them. The focus of this paper is to explore these barriers and bring the voice of people with disabilities, particularly women, to the attention of health planners and implementers.

2. Research design and methodology

2.1 STUDY PURPOSE

The purpose of the study is to examine barriers to accessing health services for people with disabilities in northwest Syria. The study also examines the prevalence of disability among the beneficiaries from SAMS' services and SAMS' staff as indicated in the research questions below.

2.2 RESEARCH QUESTIONS

RQ#1 What is the prevalence of disability in NWS?

a) Among SAMS beneficiaries
a) Among SAMS' staff

RQ#2 What are the most reported barriers to access health services for people with disabilities in Northwest Syria?

a) Financial barriers
b) Structural barriers
c) Attitudinal barriers
d) Communication barriers

RQ#3: What are some of the key recommendations to provide disability-inclusive services?

a) To SAMS and other healthcare providers in Northwest Syria
b) To the donor community and development partners
c) For future research

2.3 SAMPLING, DATA COLLECTION TOOLS AND RESEARCH ETHICS

To best address the research questions for this study, we used a mixed methods research approach, including a thorough desk review, qualitative interviews, and quantitative surveys.

Table.1: Summary of the research methods and tools

Method	Sampling	Source	Number
Desk review	NA	Open source	17 articles
Quantitative community Survey (CAPI)	Random sample	SAMS beneficiaries or their family members	208 (for 688,000 beneficiaries)
Quantitative staff survey (self-reporting)	All staff	SAMS staff	713
Key informant interview	Purposeful sampling with maximum variation	4 PWD 4 SAMS staff 1 DPO 1 Local authority 50% females	10

Quantitative surveys for a random sample were used to measure prevalence of functioning disability among SAMS' beneficiaries and to further examine perceived barriers to accessibility and potential ways to remove them. Another quantitative survey was used with a sample of SAMS' staff to measure prevalence and staff perception of the inclusion practices currently implemented by SAMS.

We also used key informant interviews, as the study aims to examine personal experiences of people with disability to identify detailed barriers, coping mechanisms and opinions about recommendations from participants.

More details about the tools and method of data collection are provided below.

2.4 QUANTITATIVE SURVEY

Community survey

During the research, authors conducted a quantitative survey for a random sample of SAMS' beneficiaries utilizing computer-assisted personal interviewing (CAPI) methodology . The interviews were conducted by trained enumerators (SAMS' data collection team) who used their mobile phones to record the answers. Enumerators received 2 hours of training on using the survey tools.

20 enumerators conducted an average of 15 interviews each to ensure timely and quality data collection. Additionally, electronic data capture via enumerators' smartphones contributed to data quality, consistency, and collection efficiency by streamlining fieldwork and reducing measurement and data entry errors.

Printed copies of the answer choices were made available for the participants to reduce the time needed to complete each interview. If participants have any barriers to reading the answer options, enumerators read out the options for them.

Data was uploaded immediately and daily, which allowed for the consultant to review the data and discuss any inconsistencies or implausible values with the enumerators. During the data collection process, SAMS' disability consultant remotely supervised data collection in conjunction with SAMS' staff. The consultant maintained detailed documentation of all issues encountered in a tracker which was used in the data cleaning process. Survey questions included two main sections; the first section was using questions developed by the Washington Group for disability statistics (WG) to gain information on the different disabilities of persons with disabilities included in the sample. All questions from the WG Enhanced short set of disability questions (WG Enhanced) were used in combination with some questions from the WG set of questions on child functioning in cases where the respondent was a child or answering on behalf of a child with a disability.

The second section of the survey focused on barriers to accessibility to health services for emergency and non-emergency health services related and not related to the impairment of people with disability.

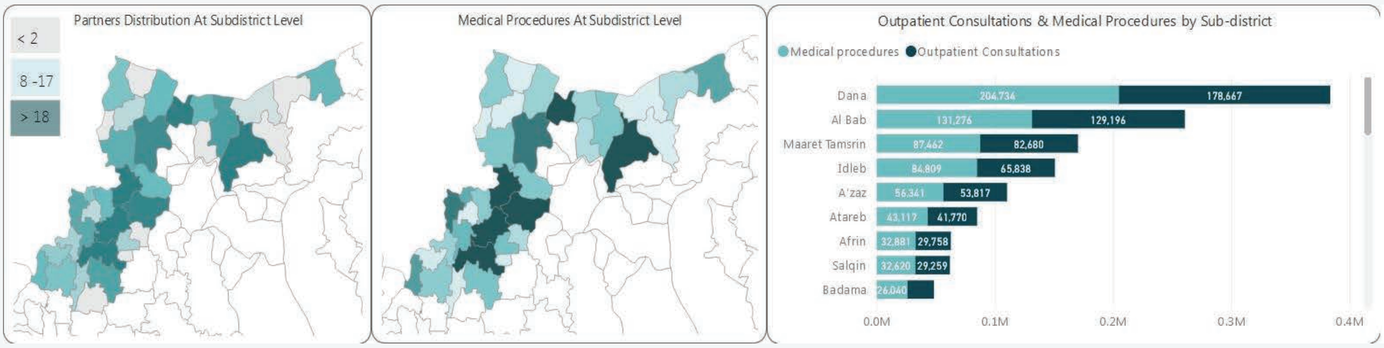
Sampling strategy

SAMS reached a total of 668,000 beneficiaries in the first half of 2022. This sample cannot be considered representative of the entire NWS' population for the following reasons:

- The distribution of SAMS' facilities is not equal to all communities.
- It is not possible to guarantee that there is equal access to people with different gender, socioeconomic status, living conditions and other factors.
- There are gaps in the services provided as shown in map 1 below.
- Unequal distribution of health facilities on communities as shown in map 2 below.
- There are factors that affect the prevalence of disability such as gender and displacement that need to be considered.

Figure 1: Map of Distribution of health facilities based on geographic reach (HeRAMS, August 2022)

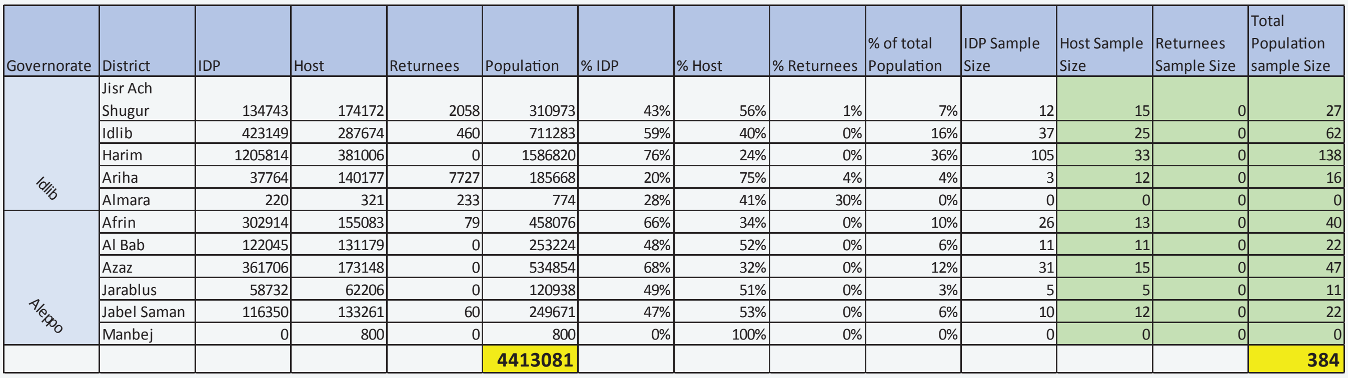
Figure 2: Map of Distribution of health services at sub-district level (Health Cluster, August 2022)



Determining sample size

Factors such as population density, gender (prevalence of disability among men is higher than women) and displacement (internally displaced people have higher prevalence of disability) were considered using data from Humanitarian Needs Assessment Program (HNAP) of the total population 4,413,081 that includes host, IDP and returnee communities (HNAP August 2022) in determining the sample size as follows:

Table.2 Geographic distribution of the population in Northwest Syria



Governorate	District	IDP	Host	Returnees	Population	% IDP	% Host	% Returnees	% of total Population	IDP Sample Size	Host Sample Size	Returnees Sample Size	Total Population sample Size
Idlib	Jisr Ach Shugur	134743	174172	2058	310973	43%	56%	1%	7%	12	15	0	27
	Idlib	423149	287674	460	711283	59%	40%	0%	16%	37	25	0	62
	Harim	1205814	381006	0	1586820	76%	24%	0%	36%	105	33	0	138
	Ariha	37764	140177	7727	185668	20%	75%	4%	4%	3	12	0	16
	Almara	220	321	233	774	28%	41%	30%	0%	0	0	0	0
Aleppo	Afrin	302914	155083	79	458076	66%	34%	0%	10%	26	13	0	40
	Al Bab	122045	131179	0	253224	48%	52%	0%	6%	11	11	0	22
	Azaz	361706	173148	0	534854	68%	32%	0%	12%	31	15	0	47
	Jarablus	58732	62206	0	120938	49%	51%	0%	3%	5	5	0	11
	Jabel Saman	116350	133261	60	249671	47%	53%	0%	6%	10	12	0	22
	Manbej	0	800	0	800	0%	100%	0%	0%	0	0	0	0
					4413081								**384**

Sample size of the 668,000 patients reached by SAMS per half year was calculated to be 384.

Margin of error	5%
Confidence level	95%
Population size	688000
Response distribution	50%

However, due to limitations related to reach and human resources available to participate in this study, the sample had to be further reduced to include 213 participants (only 207 of whom gave consent to participate and were therefore included; the remaining 6 were not) the following:

SAMS' staff survey

A survey in both Arabic and English was shared with all SAMS' staff. 713 participated, a little less than half of all staff that could be surveyed. The survey included Washington group short set (WGSS) questions to measure prevalence among SAMS' workforce. All WGSS questions were used, with an addition of two questions to explore whether the staff member uses an assistive device and its type. Understanding the specific needs of staff would help SAMS with its own inclusion plan.

Questions to explore the personal experiences, attitudes and views of staff were also included to help SAMS establish a baseline of staff perceptions regarding barriers to inclusion and accommodations. The survey was distributed by SAMS' data collection team and was anonymous, with no names or identifying information requested from participants.

2.4 KEY INFORMANT INTERVIEWS

Semi-structured interviews were designed to collect data. Participants were selected through purposeful sampling with maximum variation. 10 individual interviews were conducted with 4 groups of the following: people with disabilities, SAMS' staff, a disabled persons organization, and local health authority staff.

The survey used semi-structured online interviews, using a generic interview guide developed specifically for this study to collect data. Interviews were digitally recorded and transcribed verbatim. Participants were provided with an information sheet, explaining the study for them, and obtaining their verbal consent, while reassuring them about the anonymity and confidentiality.

The sample includes 4 people with disability (2 men and 2 women). Sampling strategy for PWD is shown in **Table.4**. All people with disabilities were able to participate directly in the interview.

SAMS' staff who participated in our study had at least one year of work experience with people with disabilities. Characteristics of SAMS' staff samples are provided in **Table.5** below. In addition, 1 NGO worker specialized in supporting people with disabilities was interviewed, as well as 1 manager as well in the local health authority **Table. 6** summarizes the characteristics of study participants.

Table. 4 PWD participant characteristics

Age	16-58 years old
Gender	2 Women and 2 Men
Location	From 4 SAMS' rehabilitation centers
Background	A mixture of physical, intellectual, single, married, young, old, severe, and moderate disability.

Table. 5 SAMS staff characteristics

Years working with SAMS	3-5 Years
Gender	2 Women and 2 Men
Type of work	2 Admin and 2 Health providers
Background	A mixture of emergency, non-emergency, disability specific and nonspecific care providers.

Table. 5 SAMS staff characteristics

Years working in the field of disability	More than 5 years
Gender	1 Woman and 1 Man
Type of work	1 working with DPO and 1 with government
Background	A mixture of management and frontline worker

2.5 Thematic analysis

For key informant interviews and the quantitative survey, questions were selected based on the WHO' inclusive-health model (WHO, 2020) with themes of financial, attitudinal, structural/physical, and communication barriers.

Transcripts from KIIs were also analyzed with an inductive approach to identify new emerging codes and themes not previously identified within the WHO model. The WHO model was flexibly used with the potential for adaptation to demonstrate this study's findings within the results and recommendations write-up. The WHO model also served the purpose of structuring potential interventions/adaptations that could serve as recommendations for implementation and policy decisions.

To ensure reliability of the data coming from the KIIs, two steps were taken. Firstly, triangulation of sources was used by interviewing both family and staff members in a given area. Second, the data was cross-checked with the findings of the community quantitative survey. The same thematic model was used with both assessment tools to ensure comparability.

Quotes that highlight the specific context of Northwest Syria were added in the results and reflection section of the paper and were chosen at random based on their selected themes and subthemes.
The following themes (Table. 7) with corresponding sub-themes were used to design both the KII and quantitative survey tools.

Table.7 Themes and subthemes for barriers

THEME	SUBTHEMES
Financial Barriers	1. Cost of services 2. Cost of transportation 3. Competing priorities
Structural Barriers	1. Service availability 2. Accessibility to the facility 3. Waiting times 4. Accessibility within the facility

Attitudinal Barriers	1. Healthcare professional attitude and mentality 2. Healthcare staff knowledge of the rights' of people with disabilities and their needs 3. Prejudice, stigma, and discrimination 4. Lack of policies in place to accommodate the needs of people with disabilities.
Communication Barriers	1. Information about availability of services 2. Information about how to access services 3. Limited availability of written material or sign language interpreters at health services. 4. Health information may be presented in complicated ways or use a lot of jargon.

2.6 ETHICAL CONSIDERATIONS

Voluntary participation

Participating in the interview and surveys was voluntary. The participants were clearly informed verbally and within the written content of the tools that their participation was entirely voluntary. If they agreed to take part, they did not have to answer any questions they did not want to and could withdraw at any time if they so wished, without giving a reason. Training of enumerators included a section on how to react if the participants wished to withdraw.

Informed consent

Before taking part in the survey or interview, participants gave their informed consent to do so. To be informed, we prepared an introduction for enumerators and interviewers to read before and obtain consent before commencing the interview. By the end of the introduction, the participants were able to understand the purpose of the survey, what was expected of them, and their right to withdraw.

No children were interviewed or included in responding to the survey. If a family member was responding on behalf of a child, appropriate arrangements were made by the enumerators to ensure that no emotional harm was unintentionally done to the child.

Anonymity and confidentiality

The privacy of the participants was prioritized in the interview and survey process. This means that all their responses have been kept confidential and anonymous. Steps were taken to ensure that it is not possible to identify a participant from his or her responses. The interviewer and enumerators reassured the participants that their contribution would be anonymized and kept confidential, and that their privacy would be protected in subsequent products using the information collected during the consultation. Video recording or taking photographs of the interview process was not permitted.

Selecting Participants

No participant who wished to take part in the survey while being at the hospital during the survey days was excluded from the process for reasons based on their ethnic group, religion, gender, or other discriminatory factors. Inclusion criteria for both the community sample and the purposeful sample included equal representation of men and women, IDPs and host communities, and other relevant variations.

Offer of compensation

No compensation was offered for any participant whether taking part in the survey or key informant interviews. This included not offering transportation costs or any other compensation.

Participants were clearly informed before starting the interview or completing a survey that their participation would not be compensated.

Accountability to affected populations

Participants were offered an opportunity to have access to the final research report. This is to ensure that their contribution and time is appreciated. SAMS will host a meeting at the community level to publish the results and explain the benefits of such research to their communities.

Safeguarding/Protection from harm

Interviews took place in an appropriate and safe space, and in a non-stressful manner. If a participant raised a point or an incident that was understood by the interviewers or enumerators as a safeguarding/PSEA issue, SAMS activated its safeguarding procedure. Any incident was to be reported to SAMS' safeguarding focal point with the consent of the participant.

2.7 DATA ANALYSIS

After all key informant interviews were completed, the disability consultant reviewed all interviews to gain a holistic overview of the attitudes of the respondents on the barriers and coping strategies to access healthcare services. Then, the data was organized into themes, allowing the disability consultant to structure the data in line with the research questions. After the data was organized, the consultant was able to systematically draw out key findings and quotes.

For the community survey data, the consultant used SPSS to provide options for data manipulation, visualization, statistics, and reproducible reporting. The analysis focused on identifying trends and findings as they relate to the research questions found above. For the quantitative data analysis, the consultant used descriptive statistics, t-tests, chi-square tests, and other inferential statistical tests appropriate to the variables under review.

2.8 CHALLENGES AND LIMITATIONS

There are several potential limitations to this study. Efforts were made to ensure a gender balance and that individuals with different disabilities were included in the sample, but it is likely that persons with disabilities who do not access healthcare facilities are underrepresented in the sample. This has implications for the analysis, as the level of access to certain services may be higher among the respondents included in the sample

3. Key Findings

2.7 DATA ANALYSIS

Among the population of SAMS' health services beneficiaries

In total, 207 participants (127 males, 80 females) were interviewed (213 were approached by the team, and 6 refused to give consent to participate). 72% of participants were adults (n=149) and 28% (n=58) were children.

The different difficulties experienced by participants in the community survey are summarized in **Table 8** and **Table 9** below.

Table.8: Washington group questions for adults (n= 149)

Question	No difficulty	Some difficulty	A lot of difficulty	Impossible
Do you have difficulty seeing, even with glasses?	73%	23.5%	3.5%	0
Do you have difficulty hearing, even with a hearing aid?	86.5%	12%	1.5%	0
Do you have difficulty walking or climbing stairs?	63.5%	24%	11%	1.5%
Do you have difficulty raising a 2-liter bottle of water or soda from waist to eye level?	88.5%	8%	2%	1.5%
Do you have difficulty using [your/his/her] hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?	91%	6%	2%	1%
Do you have difficulty taking care of yourself (washing and dressing)?	82.5%	11%	3.5%	3%
Do you have difficulty concentrating or remembering?	64%	29.5%	6%	0.5%

than they are in reality.

Further, the sample was limited to SAMS' beneficiaries, and findings from this study cannot and should not be generalized to the population of northwest Syria.

Moreover, some respondents for community surveys were responding on the behalf of their family members (with the consent of the person with disability), which in surveys that look at perceptions and attitudes offer a limitation in ensuring the voice of people with disabilities, particularly those with severe disabilities is truly included.

Do you have difficulty communicating (understanding or being understood)?	85%	12%	2%	1%
Question	**A few times a year**	**Monthly**	**Weekly**	**Daily**
How often do you feel worried, nervous, or anxious?	44%	14%	16%	26%
Question	**A little**	**Somewhere between a little and a lot**	**A lot**	
Question	**A few times a year**	**Monthly**	**Weekly**	**Daily**
How often do you feel depressed?	64.5%	10%	5.5%	20%
Question	**A little**	**Somewhere between a little and a lot**	**A lot**	
Thinking about the last time [you/he/she] felt depressed, how depressed did [you/he/she] feel?	54%	27.5%	18.5%	

Table.8: Washington group questions for adults (n= 149)

Question	No difficulty	Some difficulty	A lot of difficulty	Impossible
Compared to children the same age, [do/does] [you/he/she] have difficulty learning things?	53.5%	29%	15.5%	2%
Compared to children the same age, [do/does] [you/he/she] have difficulty remembering things?	60.5%	22.5%	12%	5%
Compared to children the same age, [do/does] [you/he/she] have difficulty playing?	50%	31%	14%	5%
Compared to children the same age, [do/does] [you/he/she] have difficulty accepting changes in [your/his/her] routine?	55%	26%	15.5%	3.5%

Compared to children the same age, [do/does] [you/he/she] have difficulty controlling [your/his/her] behavior?	50%	26.5%	15%	3.5%
Compared to children the same age, [do/does] [you/he/she] have difficulty making friends?	55.5%	15.5%	19%	10%

Among the adult respondents 21.6% (n=46) reported having a lot of difficulty and 5.6% (n=12) impossible in 1 or more domains which indicates a prevalence of 15.5% (n=33) with one or more difficulty, counting those having multiple difficulties as one entry.

Respondents reported difficulties in all areas, which confirms that the sample has a wide range of disabilities.

Although women had a slightly higher prevalence compared to men, this difference was not statistically significant.

Among the child respondents, 34.5% (n=20) reported having a lot of difficulty and 12% (n=7) impossible in 1 or more domains, which indicates a prevalence of 41.4% (n=24) with one or more difficulty, counting those have multiple difficulties as one entry.

Box.2 Prevalence of disability in Syria

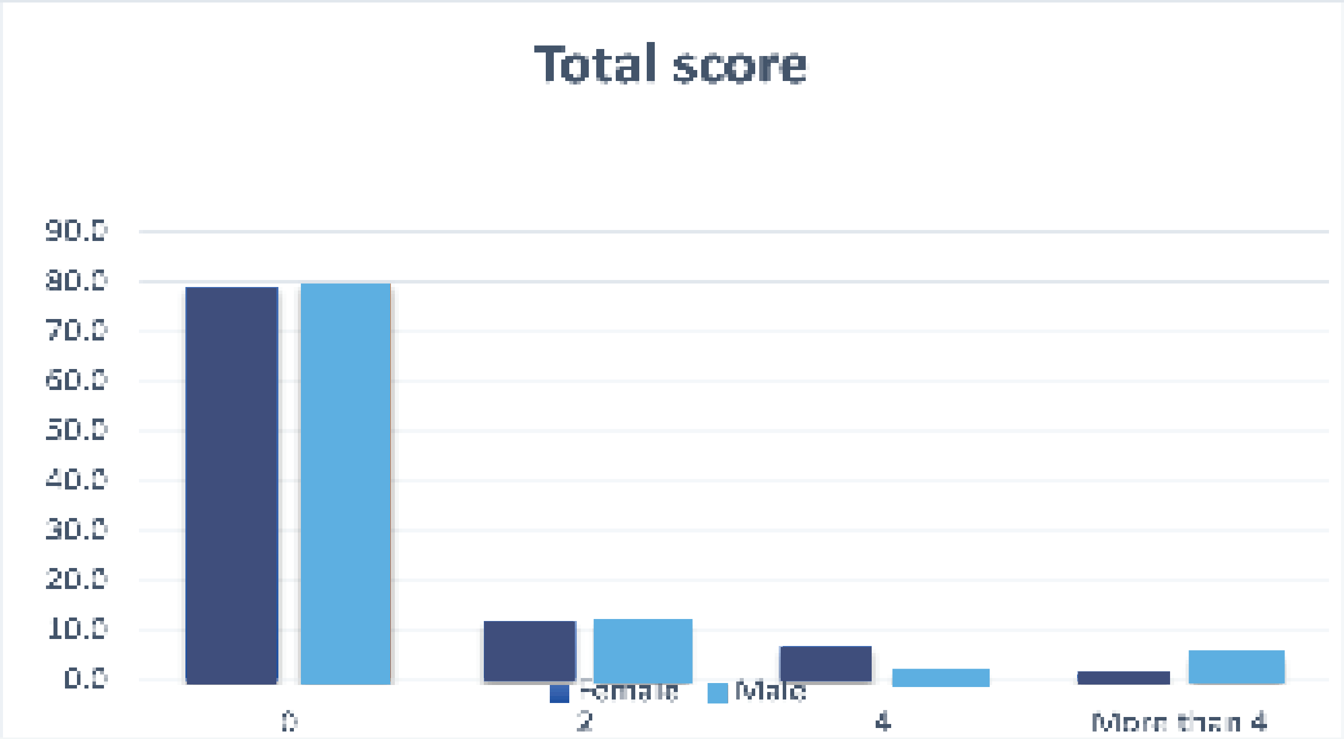
Globally, approximately 15% of the world's population has a moderate or severe disability, with the prevalence often higher in conflict- affected areas. [33]

In Syria, in 2009, the prevalence of disability was estimated to be 10% of the population. More recent studies in Northwest Syria found the average prevalence rate of disability to be 30%, doubling the global average percentage, as a recent assessment in western Aleppo, Idleb, and Ar-Raqqa governorates have declared (OCHA, 2019).

While the global estimate suggests the proportion is likely to increase to 18-20% in conflict-affected populations, this study found the prevalence in the studied sample to be comparable to the global estimates.

To analyze the prevalence of difficulty in functioning based on gender, the total score of questions was used. This score contains the sum of the score for each of the separate questions together. For each of the questions, the score was 0 if the respondent faced no difficulty, 1 if some difficulty, 2 if a lot of difficulty, and 3 if the respondents was unable to complete the activity at all. This score focused on the first 8 questions, with the possible score ranging from 0 to 24.

Figure.3: Total score based on gender



Although women had a slightly higher average score (6.9) compared to men (6.7), this difference was not statistically significant.

This score contains the sum of the score for each of the separate questions together. For each of the questions, the score was 0 if the respondent faced no difficulty, 1 if some difficulty, 2 if a lot of difficulty, and 3 if the respondents was unable to complete the activity at all. This score focused on the first 8 questions, with the possible score ranging from 0 to 24.

Among SAMS staff

In total, 713 staff completed the survey. The survey used self-reporting. 12 persons with disabilities were identified.

The different difficulties experienced by participants in the community survey are summarized in **table.10** below.

Table 10. Washington group questions for SAMS staff (n= 713)

Question	No difficulty	Some difficulty	A lot of difficulty	Impossible
Do you have difficulty seeing, even with glasses?	93.5%	6.4%	0.1%	0
Do you have difficulty hearing, even with a hearing aid?	98%	1.7%	0.3%	0
Do you have difficulty walking or climbing stairs?	91.2%	8.3%	0.6%	0

Do you have difficulty raising a 2-liter bottle of water or soda from waist to eye level?	97.8%	2%	0	0.2%
Do you have difficulty using [your/his/her] hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?	97.8%	2%	0	0.2%
Do you have difficulty taking care of yourself (washing and dressing)?	98.6%	0.1%	0	1.3%
Do you have difficulty concentrating or remembering?	92.1%	7.2%	0.6%	0.1%
Do you have difficulty communicating (understanding or being understood)?	97.2%	2.5%	0.3%	0

Among the staff respondents 1.8% (n=13) reported having a lot of difficulty and 2% (n=14) impossible in 1 or more domains which indicates a prevalence of 1.7%. (n=12) with one or more difficulty counting those who have multiple difficulties as one entry.

Research Question 2: What are the most reported barriers to access health services for people with disabilities in Northwest Syria?

In accessing specialized health services

The top reported barriers reported by respondents when asked about difficulties when accessing special services were transportation to reach health services, followed by the cost of services that are not offered by free centers, and the availability and accessibility of information about the services.

Among persons with disabilities and their family members interviewed through KIIs, the majority reported numerous barriers to accessing specialized healthcare services. Transportation came first, both in terms of availability and cost, followed by cost of medications and the availability and cost of certain types of treatments.

STRUCTURAL BARRIERS

Key informants placed major emphasis on transportation as the most important barrier facing patients with disabilities in accessing healthcare. Public transportation systems collapsed in Northwest Syria as a result of the conflict, and other forms of transportation are relatively costly. Patients often rely on their relatives to move around or use rented transportation services, such as taxis, that are not equipped to support the needs of people with disabilities.

> **"It was hard and painful for me on the way to the hospital because of my leg joint, or when they got me in or out of the car"**
> **Man with disability**

At the same time, staff interviewees confirmed that not all of their facilities or services include transportation, and when it is included, it does not include all locations. This is a particular challenge for patients with disabilities who live in remote camp settings.

"For people who are living in the camps, transportations is really hard when it comes to going to the medical center, hospitals, rehabilitation centers, and Physical therapy sessions." A worker in a special health services center.

At the same time, staff interviewees confirmed that not all of their facilities or services include transportation, and when it is included, it does not include all locations. This is a particular challenge for patients with disabilities who live in remote camp settings.

"The facility's working hours are not enough. The number of disabilities is a lot in the area. And transportation for many people is only available after working hours because we need to wait for a family member to take us after they come back from work. The facility closes at 3pm. If it closed at 7 pm, I would be able to come to my sessions more often." A male patient in a specialized healthcare facility

Interviewees particularly noted that transportation also is one of the reasons why their patients do not commit to their treatment that they desperately need, for instance, physiotherapy.

"I would say transportation is the biggest challenge. Our [the facility's] car doesn't reach all the areas, so some patients don't continue their sessions." A female worker in a specialized healthcare facility

Interviews with both workers and patients did not reveal serious problems regarding equipment and facilities. The infrastructure of specialized centers seems to have been improving in meeting the needs of people with disabilities. Nonetheless, the cost of some medicines that are not readily and freely available in NGO-supported hospitals was consistently reported as a major challenge. The issue was mainly related to cost and not just availability.

FINANCIAL BARRIERS

Although 94% (4% chose not to respond, and 2% answered “no” to the question) of respondents confirmed that they received the specialized healthcare services free of charge, financial barriers continued to be reported as one of the top barriers to their access to specialized healthcare. The main financial barriers reported by participants were the cost of transportation and the costs for medicines or some types of services that are not available at free centers. Services or equipment that are needed by fewer people in the population often receive less attention and financial support by organisations. Some private facilities provide these services, but patients must pay for them out of pocket. When they are available, they are present in fewer locations, which increases the cost of transportation, and the services themselves are often very costly.

Interviewees specifically noted the distance to the facility (for example, in the Bab Al Hawa area) was a barrier and thus required persons with disabilities to pay for transportation.

“Transportation is a problem sometimes. For example, here in Idlib, not all the areas are serviced, so people need to go to other areas, which is very expensive for them” A disabled people organisation worker

Respondents also reported that the uncovered costs sometimes forced parents to delay treatment for their children with disabilities.

“I have seen many cases here where people get artificial limbs, and need to adjust or change it after a while. But sometimes the place where they got it has closed, or is no longer receiving any support [and therefore charges for services].” A physiotherapist in one of SAMS’ facilities.”

Furthermore, other specialists highlighted the issue of availability and cost of specialized equipment by saying:

“I would say transportation is the biggest challenge. Our [the facility’s] car doesn’t reach all the areas, so some patients don’t continue their sessions.” A female worker in a specialized healthcare facility

“I would say transportation is the biggest challenge. Our [the facility’s] car doesn’t reach all the areas, so some patients don’t continue their sessions.” A female worker in a specialized healthcare facility

The same concerns were reported by both patients and practitioners regarding medications, particularly those used for chronic conditions.

“There is a shortage in medication availability for my condition [multiple sclerosis]. Now, most organizations don’t provide it. I live in pain and these medications can really improve my life. Some pharmacies can find them for me, but I can’t afford them. My sons are already working 2-3 jobs to support my needs” a female patient in rural Aleppo.

Key informants also placed a major emphasis on certain specific treatments needed by children that parents struggle to find or pay for.

"You asked about things that parents talk about when they visit clinics. Medicines are the top thing that parents are struggling with" An admin worker in one of SAMS facilities.

Another worker in a facility that offers special services to children noted that neurological assessments and treatments are in high demand, but there is an issue of availability and cost.

"Neurologists are highly requested, but some people cannot afford a visit to the hospital. Without that consult, we can't really make progress with our intervention plans" Male patient

Interviews with workers, patients, and local health authorities or NGOs confirmed that economic conditions have a big impact on people with disabilities' access to specialized healthcare. Despite the extraordinary efforts by providers of special health services, the costs of transportation, costs of some medication for chronic diseases, and costs of specific services/treatments that are not common, remain top barriers. With the deterioration of the economic situation, these barriers are exacerbated.

COMMUNICATION BARRIERS

Information about availability of services was the third top reported barrier by participants. A deeper look into the type of information indicated that this is more specific to special services, surgeries, and providers of certain medications.

"After searching for a while, I went to charity pharmacies, and they asked for medical reports since the prescription from the government [Syrian Regime area], then they told me that they can't provide such medication here." Female patient from Rural Aleppo

Key informants identified waiting times as a challenge but not a barrier – the challenge was not setting an appointment, but rather waiting time to meet the doctor due to the large need as compared to the number of available doctors.

"In Bab al-Hawa hospital we need to wait for a long time, and it is hard and painful for me to wait for the doctor to arrive." Male patient

Although sign language and other services to improve communication were not reported to be available, very few participants reported them as a barrier. When patients were asked about these specific barriers, they reported reliance on their family members to understand and pass the information to them when needed.

"There is an issue with the availability of a sign language interpreter in every clinic, pharmacy, or hospital just like in Jordan and Egypt. For example, when a man with

severe hearing loss comes to the pharmacy to get medicine without a caregiver, he can’t explain what he wants” A disabled organisation worker.

ATTITUDINAL BARRIERS

Participants highlighted the attitude of workers in special health centers as generally positive or very positive. Workers seem to understand the specific needs of people of disabilities and have the knowledge and training to address them.

“My experience is positive; the staff and the management are very nice and kind” male patient from Idlib.

Interviewees particularly noted the high level of empathy shown not only by trained specialists but by all staff including admin and support staff. Several interviews indicated that staff often step out of their original role to support a patient entering or moving around the facility.

However, attitudes of staff were one of the key areas that had a slight (but not statistically significant) difference between special and general services as shown in the general services section below.

ATTITUDES TOWARDS SPECIALIZED HEALTH CARE

Respondents who did access specialized healthcare services were asked to what degree they agreed or disagreed with several statements related to the specialized healthcare (See: Table.11). The most negative attitudes were displayed towards the ease with which persons with disabilities could access the facility (transportation) while the most positive attitudes were displayed towards the attitude of staff and how they deal with patients. No statistically significant difference was found between the responses of male and female participants.

Table .11 Attitudes toward specialized health care (n=61)

Statement	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Healthcare facility is well designed to provide services to persons with disabilities.	16%	60%	13%	8%	3%
Access to the facility (transportation) was easy	30%	50%	12%	6%	2%
Staff had the knowledge and skills to provide services to persons with disabilities and meet my specific needs	22%	60%	16%	2%	0
Staff was supportive and communicative	29%	60%	9%	1%	1%

Among respondents who used general healthcare services, again, some reported making use of private healthcare services. Among others, reasons for using private healthcare are proximity to their houses and lower wait times.

Facilities are often crowded and this can complicate movement from room to room. Furthermore, respondents reported that hospitals have no special equipment for the disabled in the ambulance and have no special beds for those with special needs. Like specialized healthcare facilities, primary healthcare facilities are often remote to the house of the person in need and cost of transportation is one of the major barriers.

No significant difference was found between responses of male and female participants. Similarly, no statistically significant differences were found between the attitudes of patients toward general and specialized services, indicating that barriers are perceived to be the same.

Research Question 3: What are some of the key coping mechanisms and solutions to provide disability-inclusive services?

We used key informant interviews to understand what respondents use or recommend overcoming the barriers they identified. The findings are presented below based on each category of barriers.

TO ADDRESS STRUCTURAL BARRIERS

Some Respondents explained that they have used civil defense services to cope with the issues of transportation and ease of access to both specialized and general healthcare facilities.

“For cases that need transportation they do contact the civil defense, and sometimes they help, once or twice.” Woman therapist from Idlib

Civil defense was repeatedly reported as one of the coping mechanisms for patients to deal with the transportation issues. This seemed to be a short-term solution and not an established mechanism between civil defense and the healthcare facilities.

“Sometimes the civil defense provides an ambulance for the patients, but not all the time because they have a lot of pressure and requests” Woman admin worker in a SAMS’ facility

Transportation is one of the major barriers for people with disability and they use these coping mechanisms to overcome challenges related to the cost of transportation, availability, and comfort. Civil defense provides ambulances which are free, comfortable for patients and patients receive support to move from their residence into and out of the vehicle. This represents a model of what people with disability reported as a solution to the barriers related to the ease of access to both specialized and general healthcare services.

“The center provided a car for our transportation, but before that, I used to contact the civil defense” Woman with disability from Aleppo.

In the absence of a wide scale solution to the transportation issue, and the lack of accessible and affordable public transportation, other solutions proposed by the respondents focused on two areas: first, the provision of transportation by the healthcare facilities, healthcare organisations, and civil defense. The second solution was the provision of cash assistance or individual support to remove the financial barriers related to transportation which will be explained in the section below.

TO ADDRESS FINANCIAL BARRIERS

In this section, we will focus on the top three costs that were reported by respondents as a financial barrier that reduced their access and commitment to the treatment they need. The costs were primarily the cost of transportation, the cost of some medications, and the cost for specific diagnostics and treatments that are not widely available in their communities.

As a coping mechanism, respondents explained that sometimes they receive support under protection services to cover these costs or help them to identify sources of support. The research also indicated that sharing information about available free services was also found to help. Further, referral pathways were used by some patients to access alternatives, and strengthening those referral pathways with integration with protection actors and services could offer further means to remove barriers.

Humanitarian healthcare providers often struggle to secure funds to cover costs to provide medications or tertiary healthcare services that are relatively expensive and cover rare conditions. Despite the extraordinary efforts of humanitarian organisations to make healthcare services available free, they often need to show good value for money for their services and deal with funding cuts that force them to prioritise basic and widely needed services. To cope with the demand of the most marginalized groups, these healthcare providers continue to advocate for donors to allow certain types of support (for example, cost of transportation, or high- cost surgeries) and often try to find alternative ways of funding them.

Finally, improving collaboration and Integration between different sectors to address the unique and holistic needs of people with disabilities. For example, linking cash assistance, protection services and healthcare support would help people with disability to cope with barriers of supply of certain services or to remove barriers that are specific to their conditions and unique circumstances.

However, as shown in the section below, the high levels of empathy towards people with disabilities within the healthcare providers and wider communities in northwest Syria have potentially masked the need to change certain attitudes to be more responsive to the needs of people with disabilities

TO ADDRESS ATTITUDINAL BARRIERS

This research found evidence to suggest high levels of empathy towards people with disabilities. Even though the attitudes of healthcare staff were overwhelmingly rated as positive and very positive by the respondents, there is still a need to look at the coping mechanisms that could help to improve access for people with disabilities. We will focus on two areas: Empowering people with disabilities to be more independent, and improving the conditions of healthcare within the general healthcare facilities.

People with disabilities mostly depend on a family member to access healthcare services. This includes booking the appointment and use of transportation to get to the facility. This coping mechanism has been widely reported by the respondents and seems to be working to overcome potential challenges related to the lack of accommodations and adaptations in the appointment and transportation systems. Having said that, we continue to encourage healthcare providers to improve accessibility of these means and have a more empowering attitude towards promoting the independence of people with disabilities. For instance, appointment systems should accommodate for patients who have issues in seeing, hearing, and speaking. Furthermore, ambulances and patient transport vehicles should consider situations where the person with disability is not accompanied by a family member.

The second area of support is related to improving the conditions within the healthcare facility. The prevalent attitude observed in this study is that healthcare providers provide conditions to service to all patients. While the needs of people with disabilities might differ, it appears that providers rely on the high empathy and behaviour of staff to support these specific needs. For instance, it was reported that admin staff (receptionists, guards, drivers) support the transfer of patients from the vehicle to inside the facility, and this is beyond their scope of work. It is recommended that such support should be systematic and attitudes toward the need for special considerations for the needs of people with disability change. One patient gives a good example of this

“People with paralysis should have special treatment. In terms of appointments for example. They can’t wait in the waiting room like everyone else.” Beneficiary

In summary, coping mechanisms provide workable solutions that improve accessibility to healthcare for people with disability. They should not mask the need to introduce accommodations that improve independence and experience of people with disability. Practices related to patients’ care used in specialized healthcare facilities offer a good starting point to generalize to general healthcare facilities.

TO PROVIDE DISABILITY-INCLUSIVE HEALTH INFORMATION

“Some patients with disabilities don’t know how to book an appointment, sometimes they come without an appointment from far places, where we let them in.”
A receptionist in a general healthcare facility.

This is an example of how some facilities accommodate the needs of people with disabilities. Information about availability and how to access healthcare facilities are predominately designed for people without disabilities, with the assumption that either a family member or the system itself would accommodate for the needs of people with disabilities. Very little evidence was found on considerations specific to the needs of people with disability. For example, having interpreters fluent in sign language is not a common practice. Lists of services and referral pathways are shared in ways that assume users can access written information on smart phones. Practices in specialized healthcare services seemed to work better for people with disabilities. More attention was offered in terms of time and communication to ensure patients themselves understand their rights and sources of support they can access.

“In other centers [General healthcare hospitals], they just tell me what to do, but in this center [A specialized healthcare facility], they do a follow-up, and ask us if we understand instructions during the session” Male patient with disability from rural Aleppo.

Another example of a coping mechanism was linking the patient with a case worker (from child protection or protection services within the same organisation) to provide more individualized support that included information sharing and support to identify additional services.

“In case the patient needs a service not available at the hospital an arrangement between the hospital and other hospitals in the area can be made. Protection teams help with this” A female therapist from Idlib.

In summary, making information about healthcare services more accessible to people with disabilities were listed as a top priority by patients for both specialized and general healthcare services. Existing coping mechanisms indicate that the challenges in providing those accommodations are partially related to the attitudes and capability of of healthcare providers. Both can be addressed without a huge financial investment by adopting a universal design approach for information sharing. A universal design approach ensures a review, by design, to the means of communication with people with disabilities and ensure they consider different abilities. High empathy and widely used (and cheap) technologies offer opportunities to improve the accessibility of people with disabilities to information. In the next section, we will discuss some of these recommendations in more detail

Recommendations

The recommendations below capture some of the potential solutions that are specific to the context and capacities in northwest Syria and build on the coping mechanisms that were reported by the participants who included patients, healthcare workers, an NGO that works with the disabled and local health authority representative. The recommendations were organized based on the theme of the barrier, specific barrier and specific recommendations to ensure they are more actionable to the actors listed below.

RECOMMENDATIONS FOR SAMS’ IMPLEMENTATION AND OTHER HEALTH SERVICE PROVIDERS

Theme	Topic	Recommendation
Structural barrier	Transportation	• Provide patients with information on available NGOs/Resources that offer transportation support

Theme	Topic	Recommendation
Structural barrier	Transportation	- Strengthen coordination with the Syrian civil defense and NGOs that can offer transportation support. - If resources allow, scale up transportation support for patients with disabilities based on specific vulnerability criteria. Prioritize those whose conditions present challenges that reduce their access to services (Remote areas, mobility challenges, temporary camp setting, etc.)
Structural barrier	Accommodations to the facilities	- Conduct assessments to understand physical accessibility barriers in the available healthcare facilities. - Prioritize adaptations that offer the most challenges based on consultations with people with disabilities who are the existing recipients of SAMS' services. - Consider micro-grants, community-based or community-led initiatives to improve accessibility, preferably led by disabled people or organizations that represent them. - Engage with youth-led initiatives and other community-based organisations who could provide volunteers to assist people with disabilities. For instance, volunteers that can help at the reception, waiting room and mobility to and within the facility. - Engage with the coordination mechanisms (the UN cluster system, Local health authority, etc.) to define and mainstream minimum standard accommodations and adaptations that must exist in all facilities and transportation services. This could help donors to prioritize funding them. - Provide counseling to family members of persons with disabilities on the importance of their active support for their disabled family member to live a fulfilling life.
Financial barriers	Cost of transportation	- Collect information about the patients' locations, with a focus on patients with disabilities, to help prioritize transportation services for those in severe need and the cost of tran-

Financial barriers	Cost of transportation	• -sportation services for those in severe need and the cost of transportation present a barrier to their accessibility and commitment to services. • Ensure information about support services (when available) are presented to patients with disabilities. This includes referrals to cash assistance and protection services that can provide transportation services. • Conduct mapping of existing services provided by SAMS along with maps of other services to ensure patients with disabilities are using the ones closest to their residence. • Advocate for donors to include transportation cases as an eligible cost for SAMS' protection services that can be used in specific cases to remove barriers to accessibility for patients with disabilities. • Consider integration of general healthcare services within specialized healthcare facilities to reduce the need for travel for patients with disabilities. This is particularly important in centers that offer services to children with disabilities. For instance, having neurologists and pediatricians rotate to visit centers for children could reduce travel cost for their parents.
Financial barriers	Cost of medications and services that are in short supply	• Ensure information about last resorts for free tertiary healthcare services and medications for chronic diseases are updated and made available to patients with disabilities and SAMS workers. • Work with the existing coordination mechanisms to ensure information about actors that can support with cash assistance, protection case management or referral to free tertiary and chronic disease medications are known to patients with disabilities.
Attitudinal barrier	Universal design to promote independence and inclusion of people with disabilities	• Train healthcare leaders and senior staff on universal design for healthcare. Use the training to identify wide scale low-cost initiatives to improve the accessibility and experience of patients with disabilities.

Attitudinal barrier	Universal design to promote independence and inclusion of people with disabilities	• Implement training and awareness raising programs for the family members of patients with disabilities on how to promote their independence in accessing healthcare services. Use this engagement to further understand the positive and negative coping mechanisms to improve how services are offered. • Review appointment systems and waiting time to include accommodations for patients with disabilities. This should include adaptations that are shaped based on consultations with the patients themselves. • Generalize practices that are working in specialized healthcare centers to general healthcare facilities by creating peer to peer learning opportunities between staff who have experience working with people with disabilities and those in general healthcare facilities. • Introduce agents of change in SAMS' general healthcare facilities. For instance, social workers who can gradually introduce practices that improve the experience of patients with disabilities. Engage with protection actors or disabled people organisations if resources do not permit adding more human resources to drive the change towards universal design in your organisation.
Communication barrier	Information about services and support	• Review how information is shared with patients to ensure they are accessible by people with different abilities and reduce reliance on family members for support. This should include appointment systems, access to information about the patient's care, rights, and available services in their communities. • Pilot initiatives to improve accessibility to information to be used as models for other healthcare actors and for advocacy with donors. These initiatives should preferably ensure integration with other sectors, to be community-led initiatives, to include patients with disabilities or disabled people organisations and ensure sustainability.

RECOMMENDATIONS FOR DONOR COMMUNITY

Theme	Topic	Recommendation
Structural barrier	Transportation	• Work with other donors and development partners to explore wide scale solutions for the gap in public transportation. Identify opportunities to support sustainable and community led solutions to improve the public transportation services. For instance, prioritize livelihood or cash for work opportunities that increase the availability and affordability of transportation, with a focus on people with disabilities. • Remove policy barriers that prevent healthcare providers and other actors from using available resources to support patients' transportation, particularly those who meet specific vulnerability criteria developed by the affected community and their services' providers.
Financial barriers	• Cost of transportation • Cost of medications • Cost of • certain tertiary healthcare services	• Costs are driven by shortage of supply and increase in demand. Donors are encouraged to revisit policies that limit the ability of healthcare providers to access funds that include these services. Value for money considerations should prioritize equity and not just economy. Donors should make room for downstream partners to include some of these services by revisiting how projects are evaluated and include equity indicators. Indicators and success criteria that prioritize responding to the needs of most vulnerable people with disabilities. • Work with other donors and civil society organisations to develop a road map that includes a long-term action plan (5 year) and transformational agenda to promote inclusion of people with disabilities.
Attitudinal barrier	Universal design and empowerment of people with disabilities	• Prioritize initiatives that promote the centrality of protection within the healthcare sector. Promote integration of protection services that include engagement with people with disabilities and community-led mechanisms. • Consider systems strengthening projects that mainstream universal design and inclusion practices that lead to wider policy change.

Attitudinal barrier	Universal design and empowerment of people with disabilities	• Create opportunities for people with disabilities to be present in consultations and different coordination fora. For example, include advisory groups made up of individuals with disability to the different planning and decision-making processes within the humanitarian and development coordination structures.
Communication barrier	Information sharing	• Support research initiatives to further understand barriers and facilitators to coordination and information sharing. This includes alternatives that are readily or potentially accessible to people with disabilities in their homes and communities. Such as radio, television programs, community gatherings and not just social media.

RECOMMENDATIONS FOR FUTURE RESEARCH

Topic	**Recommendation**
Structural barriers	• Service mapping for available services and gaps related to providers of transportation to healthcare services. This includes mapping of geographic locations of services against distance travelled by patients. The research will generate updated service maps and referral pathways for patients including those with disabilities and recommend ways to improve coordination between different providers.
Financial barriers	• Equity research to highlight the experiences of people with disabilities and most vulnerable patients. This research would look at alternatives and means to integrate livelihood and cash assistance with access to healthcare. It will further highlight the gaps in supply for certain tertiary healthcare services and support advocacy efforts to address them. • Research to investigate accessibility of people with disabilities to the workforce and sources of income. This includes market assessments and livelihood and employment opportunities including those within the healthcare workforce.
Attitudinal barriers	• Research to investigate social behavioural change communication in promoting inclusive practices in general healthcare practices. The research will look at motivation, capabilities, and opportunities of healthcare workers to implement universal design practices defined with the affected population.
Communication barriers	• Investigate means to deliver messages to people with disabilities using available resources. This includes exploring opportunities to integrate messages with local media, local community gatherings and outreach activities. The focus should be on low-cost, wide-scale and sustainable solutions including transforming existing means of communication to be more inclusive.

List of figures

List of tables

List of acronyms and abbreviations

CAPI	Computer assisted personal interview
CP	Child Protection
CWD	Children with Disabilities
FCDO	Foreign, commonwealth and Development Office (UK Government)
HNO	Humanitarian Needs Overview (from the UN)
IDP	Internally Displaced Person
ICF	International classification of functioning, disability, and health
MHPSS	Mental Health and Psychosocial Support
NWS	Northwest Syria
NGO	Non-Governmental Organization
PWD	People with Disabilities
PSS	Psycho-social support
SAMS	Syrian American Medical Society
SVRD	Severe Violence Related Disability
OCHA	UN Office for the Coordination of Humanitarian Affairs
USD	United States Dollar
UN	United Nations
WGQ	Washington Group Questionnaire
WHO	World Health Organisation

Annexes

Annex A: Assessment tools

SURVEY FOR COMMUNITY
SURVEY FOR SAMS STAFF
KEY INFORMANT INTERVIEW GUIDE FOR NGO AND LOCAL AUTHORITY
KEY INFORMANT INTERVIEW FOR A PATIENT OR THEIR FAMILY

KEY INFORMANT INTERVIEW FOR SAMS STAFF

Annex B: Bibliography

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[What all health planners and workers in Northwest Syria should know about the prevalence of disability, barriers, and recommended solutions to improve accessibility in Northwest Syria.]

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