Access to rehabilitation and specialised health services for Syrian refugee children with disabilities in Türkiye

Qualitative Study

September 2022

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Relief International is a humanitarian non-profit agency that provides emergency relief, economic rehabilitation, development assistance, and programme services to vulnerable communities worldwide.

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The London School of Hygiene & Tropical Medicine (LSHTM) is a world-leading centre for research and postgraduate education in public and global health.

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Project duration

April 2022 – September 2022

Data collection

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Ethics

Ethical approval for this study and secondary data analysis was obtained from the London School of Hygiene & Tropical Medicine Ethics Committee (Ref: 27699). The 2019 data collection from LSHTM (Ref: 17623) received local approval from Istanbul Sehir University (reference: ISU: 26/2019). During the 2022 data collection, Relief International received informed consent from all participants in the interviews and focus groups, informing them that their data would be analysed by LSHTM.

Acknowledgements

Relief International thank the following for their support during data collection in 2022: Maya Vakfi; Mülteciler Derneği; Take My Hand; SENED Organization; Fluka Alhurriye

1. Background

People with disabilities are more likely to experience health inequalities and poorer health outcomes than people without a disability [1]. This may result from an underlying health condition contributing to their disability, higher poverty levels, stigma and discrimination, and barriers to health services [1]. People with disabilities may thus have a greater need for general health services. Further, many people with disabilities require rehabilitation and specialised healthcare to support their functioning and quality of life. However, many people with disabilities face difficulties accessing health services. Barriers to access may include inaccessible transport, limited training of staff on disability, or financial constraints [1]. Despite a potentially greater need for healthcare services, people with disabilities often have lower coverage.

In 2019, the London School of Hygiene & Tropical Medicine (LSHTM) conducted a survey of 3,084 Syrian refugees living in Istanbul, estimating a prevalence of disability of 24.7% [2]. The prevalence of disability among children was estimated at 21%, with mental health conditions a major contributing factor. Unmet service need (i.e. the proportion of people who felt they need services/support and have not received, compared to those who have a need and have accessed them) was high amongst the sample, with qualitative research identifying several barriers to healthcare access, including limited information on available services and their benefit, stigma and financial constraints.

1.1. Project Rationale

With evidence estimating a high prevalence of disability among Syrian refugee children and severe unmet need for rehabilitation and specialised services, Relief International have aimed to develop new programmes and interventions to support this population and their specialised health needs. To inform this work, they have sought further evidence on the experiences, access, and barriers to healthcare among Syrian refugee children with disabilities that may contribute to unmet service needs.

1.2. Project Aim

This study aims to explore the experiences of refugee children with disabilities and their caregivers when accessing rehabilitation and specialised health services in Türkiye.

The objectives of this study are to:

1. Investigate the experiences of Syrian children with disabilities and caregivers when seeking and accessing specialised health services
2. Identify barriers and facilitators for children with disabilities when accessing specialised health services
3. Explore the impact of disability and refugee status on accessing specialised health services
4. Understand the experiences of healthcare staff providing services to children with disabilities

2. Methods

Qualitative research was conducted with Syrian refugee children and their caregivers in Türkiye at two-time periods; 2019 and 2022.

Data collection was conducted across three regions of Türkiye; Istanbul, Adana and Antakya. In-person, semi-structured, in-depth interviews were conducted with Syrian refugee children with disabilities and their caregivers, focus group discussions with caregivers of children with disabilities and key-informant interviews with workers in rehabilitation centres. Data collection for the in-depth interviews was aided by interview guides exploring the barriers and facilitators to accessing and providing specialised healthcare.

Two datasets were analysed for this current study.

2.1. LSHTM Data 2019

In 2019, researchers at the International Centre for Evidence in Disability (ICED) at LSHTM were hired by Relief International to conduct a mixed-methods study into the experiences of disability among Syrian refugees in Istanbul. The report has been published here and peer-reviewed journal articles published by Polack et al. (2021), Boggs et al. (2021) and Scherer et al. (2020) [2-4]. The qualitative data from the 2019 study is yet to be published. The subset of child-related data was analysed in the current study, as described.

In 2019, LSHTM conducted qualitative in-depth interviews with 36 people with disabilities and caregivers of children with disabilities, exploring access to healthcare, rehabilitation, and help-seeking behaviours. Within this sample, 11 were proxy interviews with caregivers of children with disabilities, and it is this data that has been re-analysed in this study. Of these 11 interviews, 6 were conducted with both the caregiver and child with a disability. Interview respondents were purposively selected from the household survey of the same mixed-methods study using pre-defined criteria in line with Patton's maximum variation sampling [5], including age group, gender, and impairment type. Data collection was conducted in Sultanbeyli district in Istanbul by two interviewers. LSHTM did not receive ethical approval to audio-record, so whilst one researcher interviewed, the other transcribed verbatim using hand-written notes.

2.2. Relief International Data 2022

In June 2022, Relief International conducted interviews with caregivers and specialised healthcare providers of refugee children with disabilities in Istanbul, Adana and Antakya, exploring their experiences in accessing healthcare, the difficulties they face, and the quality of the services provided.

In Istanbul, interviews were conducted with 19 caregivers of Syrian refugee children with disabilities, two focus group discussions were held with caregivers of children with disabilities and three key-informant interviews were conducted with healthcare providers in rehabilitation centres. In Adana, Relief International conducted 23 in-depth interviews with caregivers, three focus groups and two key informant interviews. In Antakya, they conducted 23 in-depth interviews, three focus groups and four key informant interviews.

In total, 76 individual in-depth interviews were held with caregivers of children with disabilities, nine key informant interviews, and eight focus group discussions were conducted, including 71 participants.

Interview respondents were selected through convenience sampling from local rehabilitation centres in the included regions. Relief International transcribed and translated each interview, providing LSHTM with anonymised transcripts for analysis.

2.3. Data analysis and presentation

Thematic analysis was used to analyse the data [6]. Transcripts were coded in NVivo 12 using a coding framework that was iteratively adapted throughout analysis. Emerging themes were identified and refined, comparing relationships between codes and across groups. Participant quotes and narratives have been extracted and presented in the results.

The themes identified were mapped against Levesque's Framework of healthcare access [7]. This framework has recently been adopted by the Missing Billion project to better understand healthcare access among people with disabilities [1]. Levesque's framework presents the journey from healthcare needs to healthcare consequences to understand the experiences of accessing services along the healthcare experience. It takes into consideration factors from both the providers' (supply) and users’ (demand) side and how these influence an individual’s access to care (Figure 1). For example, an individual’s ability to perceive a need for a service is influenced by both outreach programmes from health providers and the individual’s trust in the health system.

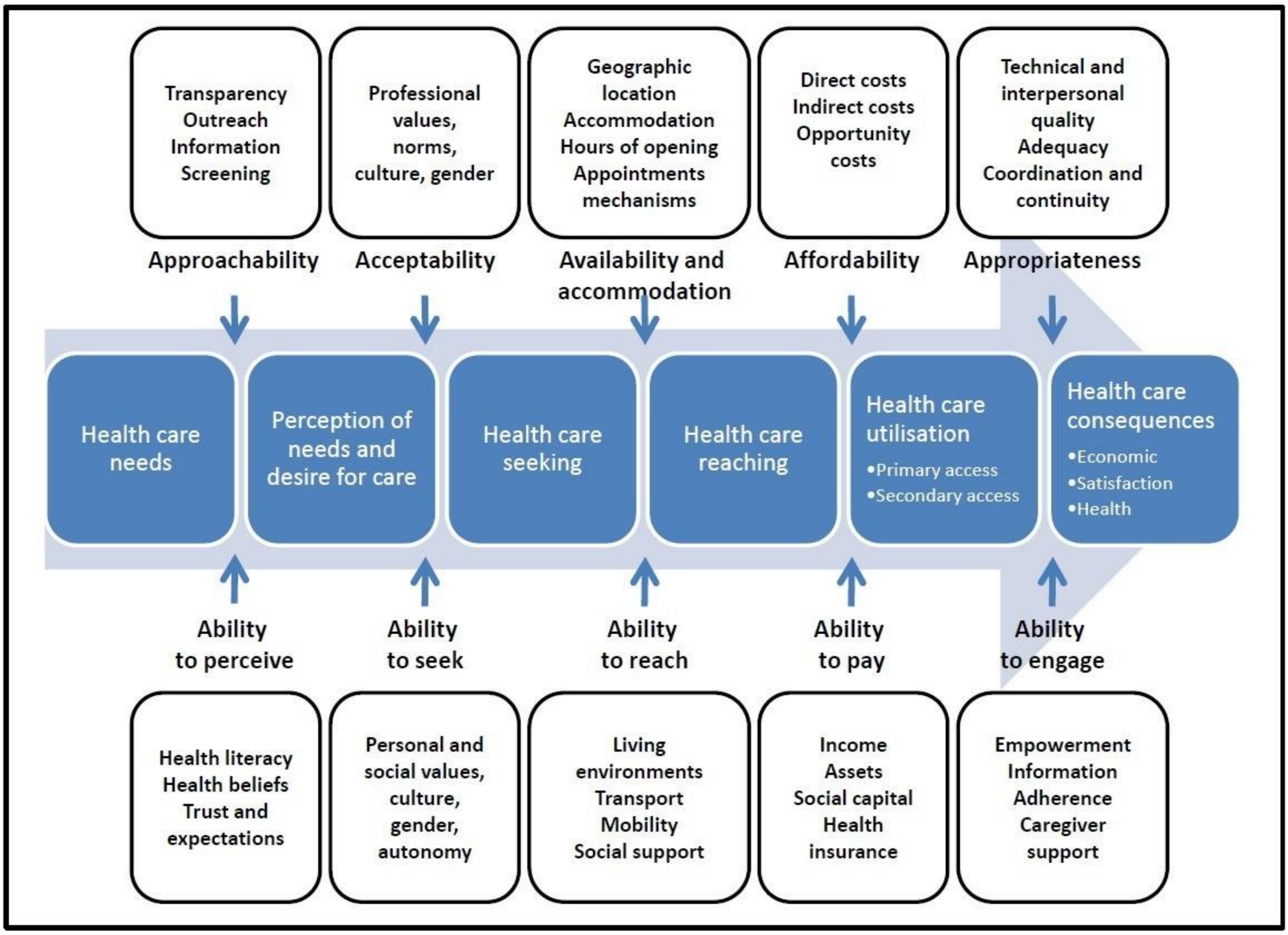

Figure 1. Levesque framework of healthcare access

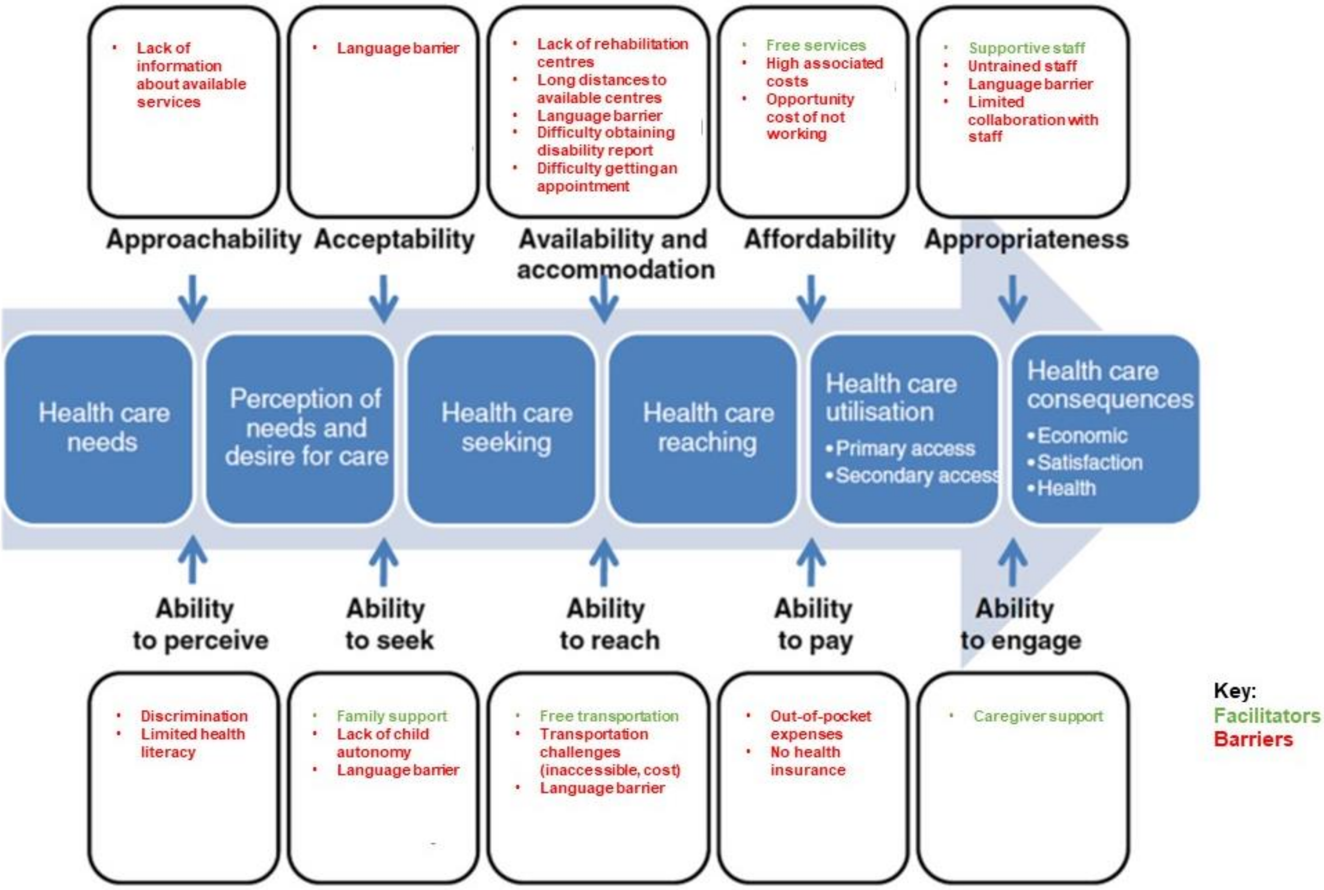

Figure 2. Barriers and facilitators among Syrian refugee children with disabilities when accessing rehabilitation and specialised health services

3. Results

The barriers and facilitators to accessing specialized health services identified in this study have been illustratively mapped against the Levesque framework in Figure 2. Note that each of these were not the experience of all; for instance, free transportation to services was a facilitator to access for those that received this, but receiving free transportation was rare.

3.1. Participants

Tables of participants can be found in the Appendices.

Included in the in-depth interviews were 76 caregivers, representing 87 children with disabilities. The majority (74%) of caregivers were female. Of the 87 children with disabilities, the majority (72%) were male and nearly two-thirds (60%) were under the age of six. Thirty-one were children with autism spectrum disorder, five children with musculoskeletal impairment (MSI), 11 with another physical impairment, five children with mental health conditions, five with intellectual disabilities, two with non-specified congenital deformities, 21 with non-specified speech disorders, two with learning disabilities, two with non-specified hearing impairment and three children with non-specified disabilities. In addition to the caregivers, in-depth interviewers were conducted with nine key informants based in rehabilitation centres; a technical manager, technical officer, a receptionist, a project coordinator, rehabilitation manager, a blindness skills therapist, a physical therapist and two speech therapists. A further 71 caregivers were included in the focus group discussions, representing 71 children. The vast majority (87%) of caregivers included in the focus groups were female.

3.2 Healthcare needs

3.2.1 Factors associated with disability

In general, only people with mental health conditions and psychosocial disabilities talked about contributing and aggravating factors associated with their disability.

Children with psychosocial disabilities were often involved in war-related experiences. Trauma and loss were reported to cause mental distress.

> *"Nothing affected my life except for the death of my uncle. [...] A bomb exploded near him, he was leaving the mosque, and he died in the hospital."* (17-year-old boy with a mental health condition)

The living conditions in Turkey have also negatively impacted on children with psychosocial disabilities. Many families experience economic hardship, with employment opportunities sparse, and Syrians can be exposed to discrimination.

> *"There is nothing good in my life, our situation is very bad. We have a lot of debt, not only because of that I wish to kill myself, but also because of Turkish people who treat us without any dignity."* (14-year-old boy with a mental health condition)

3.2.2 Caregiver wellbeing

Some caregivers discussed the impact of disability on their wellbeing. Some frequently experienced negative emotions such as sadness, distress, and fear about their child's disability. In some cases, caregivers sought support for this distress. Some caregivers reported that they were anxious and stressed when their child was diagnosed with a disability because they felt ignorant about disability and the associated health condition and/or impairment.

> *"When my husband knew that she had Down Syndrome, he felt really sad and cried a lot. [...] I feel pressured when all the people talk normal and my daughter is not."* (Female, caregiver of a child with intellectual disability)

3.3 Perception of need and desire for care

3.3.1 Discrimination

Discrimination towards Syrians and refugees was a critical issue discussed by participants. Many of the children have faced, to some extent, discriminatory attitudes and actions, including bullying and physical abuse. These had been experienced at school, work, neighbourhoods, and parks. Children were most often discriminated against by other children, although they had experienced this from teachers and educators.

> *"When I registered at the school, they thought I was Turkish. The kids were playing with me normally. When they knew that I am Syrian, they just stopped playing with me. They start to tell me to go back to Syria what are you doing here in our country."* (12-year-old boy with a mental health condition)

These experiences contributed to sentiments of distrust towards the Turkish community and their willingness to seek healthcare in a Turkish facility. Nevertheless, it seems that once the children had learned the local language, the discrimination reduced and they were able to more actively participate in their community.

Knowledge of the Turkish language contributed to an easier refugee experience. Improved inclusion in the community increased the willingness to access local services. One caregiver suggested educational interventions to overcome this issue.

> *"We have a problem here when it comes to the racism we face as Syrians. I think they should start some courses for the Turkish people in order to educate them about us and our situations. They always blame us for not getting along with them."* (Male, caregiver of a child with autism)

With regards to disability discrimination, some parents did not let their child leave the house, out of fear that society would reject them for having a disability. This fear of disability-related stigma and discrimination stopped families from integrating their child into the community and from seeking specialized healthcare.

3.3.2 Perception of need

Children with disabilities often described feeling normal when asked about their disability. However, some children said that they felt they were a burden to their parents, and this prevented them from raising disability-related issues with family and from seeking specialised care.

Further, some caregivers did not perceive a need for rehabilitation and specialised health services as they believed their child's functioning, health condition and disability would eventually improve of its own volition. Few described full understanding of their child's disability and in some instances, caregivers did not recall the name of their child's condition and associated disability.

For example, some caregivers of children with mental health conditions and associated psychosocial disabilities from the 2019 data were unaware of their child's condition.

Participants found it hard to consider formal mental health support and rather described that having a suitable support system, such as family, can help with mental health-related issues. Some explained that mental health services were more needed for the elderly and veterans than their own children. Important to note is that none of the children with mental health issues in the 2019 sample received mental health services, perhaps explained in part from this lack of perceived need.

Further, there was a limited understanding by some caregivers on the benefits of rehabilitation services, preventing them from seeking care.

> *"Without the report, we can only receive physical therapy sessions. That is not a service. I could do that physical therapy on my own. They are holding my son's leg in a certain way and moving it in a certain way. That is it. I can find that on the internet and do it myself."* (Female, caregiver of a child with physical impairment)

3.3.3 Information about health services

Most commonly, participants discovered about available specialised services through word-of-mouth, although some did receive referral from primary care. Online information, especially social media such as Facebook and WhatsApp, was also an important method to inform people about the services available. We were also told of Mülteciler, a specialised refugee centre providing rehabilitation in Istanbul, who conduct public awareness sessions to inform people from the local area about the services available.

This said, limited knowledge and information about available services was common and impacted the seeking of specialised healthcare. Some of the caregivers did not know where to go and they had difficulties finding someone to talk to or answer their questions.

> *"I would like to mention a problem we are having. There is a shortage of information in terms of where we are supposed to go and how should we deal with this whole thing. We need some sort of source to provide us with information and guide us through the process. We need information about our children's condition so we could figure out what to do."* (Female, caregiver of a child with physical impairment)

To overcome this challenge, some participants suggested a social media platform to maintain better communication with staff and the steps to take to obtain health services.

3.4 Healthcare seeking

3.4.1 Gender, autonomy and culture

We were told that women were usually the caregivers and companions of children with disabilities. However, it was believed by some respondents that women have less autonomy and more difficulty than men when seeking support, resulting from gender dynamics in Syrian culture. Some participants commented that women were more likely to stay at home, whilst others said that women do not know how to act in certain situations of distress. These factors were said to reduce healthcare seeking for children with disabilities and there were calls for empowerment of female caregivers, to build their confidence in seeking specialised healthcare.

3.4.2 Help-seeking behaviour

When initially seeking help, some respondents asked acquaintances first, others sought help at emergency/hospital services, and others asked for help directly at rehabilitation centres. However, seeking help was less frequent when children had mental health conditions, often because of the perception towards mental health services being only suitable for those with severe need. At times, mental health services were stigmatised.

> *"She started to make some strange movements, she was not socialising. You would speak to her and she wouldn't respond to you. When I saw her like this I decided to take her to a psychologist, regardless of what people say, that such doctor is for crazy people."* (Male, caregiver of child with autism)

Fear of not speaking the language was an obstacle to seeking help. Some caregivers felt afraid because they didn't know how to speak Turkish and there was fear of not knowing how to respond when asked questions by the healthcare staff. Professional values from service providers also prevented caregivers from seeking help.

> *"If I want to go inside* [name of NGO] *and ask, no one answers me. I went before to ask about registration for some course. The lady who set behind the computer kicked me off and told me to ask outside. It happened to me about two times, so I decided to never go there again."* (Female, caregiver of a child with musculoskeletal impairment and a mental health condition)

Some parents used YouTube to learn more about disability and for information on how to support their child's daily activities, such as eating. Some chose to rely on this easily accessible information, rather than visiting a rehabilitation centre.

3.5 Healthcare reaching

3.5.1 Availability of Services

Rehabilitation services were offered in government, private, and centres provided by non-governmental organisations (NGOs). Both staff and users agreed that governmental centres would only accept Turkish nationals. Private centres provided services at a very high price and there was a perception of low quality. We were told that there are few NGO-supported centres.

Take My Hand and Mülteciler Derneği were often mentioned as NGO-supported centres in Istanbul. In Antakya, Fluka Alhurriye was commonly mentioned. In Adana, participants often mentioned the Turkish Red Crescent as a place of support.

Caregivers stated that most of the rehabilitation centres were private and too expensive. And further, not all accept Syrian children. Participants told us of organisations that had turned away Syrian children because they did not have Turkish citizenship.

Distance between the hospitals and rehabilitation centres varied. Some participants mentioned having centres close to them. However, for many, long distances to the centre acted as a barrier to reaching healthcare. Long distances meant increased financial cost of transport and additional time taken from other duties, such as income generating activities and other caregiving responsibilities with siblings and the wider family.

> *"I did not continue receiving the service in many centres because of transportation. They were very far and I had a difficulty going there."* (Female, caregiver of a child with autism)

3.5.2 Mobility and transportation

Staff and caregivers agreed that transportation and mobility of the children with disabilities were problematic challenges for reaching specialised health services. Transport was expensive and many families struggled to pay. Some children used mobility devices, such as strollers and wheelchairs, that made public transport difficult. Additionally, behavioural aspects of some conditions, such as autism, challenged the use of public transportation.

> *"Also, children with special needs cannot use public transportation because they cannot interact with people, so they start screaming during the whole commute, which takes hours sometimes."* (Male, healthcare staff)

Many participants suggested the provision of free transportation or financial aid to cover transportation services.

> *"I wish you could provide transportation, because the minibus does not accept to stop for me. If I have a stroller, I have to carry her all the way."* (Female, caregiver of a child with physical impairment)

When some rehabilitation centres provided transportation, which were of great support, caregivers of children with non-physical impairments, such as autism, were those most likely to receive the service, with accessible vehicles for physical impairment and assistive products rarer.

3.5.3 Enrolment and registration

To receive most rehabilitation services (excluding PT), children with disabilities require a valid disability report issued by a governmental hospital and a residence card. To obtain this report, a medical assessment is required and booked in advance.

Although a few participants described the process as easy, most of the participants and staff agreed that getting the report was challenging. Reasons for this included language barriers and limited assessment appointments.

> *"Most centres require the beneficiary to provide a valid hospital report about the condition, and the process to obtain that*

> *report is a nightmare. People cannot get an appointment in the hospital and even if they did, there are language barriers and certain difficulties that would make the process take up to a year or more.”* (Male, healthcare staff)

Language barriers were common throughout the entire process and translation services were rarely available in hospitals and assessment centres.

> *“It was a bit difficult to get the report because when I first went to the hospital, they gave me a lot of documents and I did not know any Turkish. They did not provide a translator.”* (Female, caregiver of a child with autism)

In some situations, caregivers felt that the child was not correctly diagnosed due to their inability to speak Turkish. In many instances, hospitals refused to give a report, because they did not believe the child needed one. This meant that some needing specialised services had no way of accessing them, as they had been rejected at this key step.

Difficulty in having their child assessed was commonly experienced. Often this resulted from limited available appointments. Istanbul was thought the hardest city to obtain an appointment. Some caregivers interviewed were still waiting for an assessment to be conducted. Some had been waiting for over a year.

The disability report is only valid for one year. For those that are successful in obtaining a report, this means that they have to navigate the challenges described yearly. Getting a disability report can take two months to one year, and repeating this yearly is often not feasible.

To overcome these delays, some respondents paid to expedite the process and obtain a disability report, although this is achievable for very few people.

> *“We hired a broker and he made the appointment for us because I tried very hard and could not, and he took money from me. Though the broker didn't delay in extracting the report he took 1000 Turkish lira.”* (Female, caregiver of a child with congenital condition)

Whilst some participants were unable to obtain the disability report, others chose not to obtain it. This included only mothers of children with autism who feared having children classified as having a disability.

For those that did obtain a disability report, children would be referred to a nearby rehabilitation centre for registration. However, there was reported a lack of available rehabilitation appointments and some participants had not received rehabilitation services at the time of the interview, despite having a disability report and seeking services for months. These delays had led to medical complications and worsened impairments for some children.

> *“My son’s condition was not that bad one year ago. However, the waiting made it worse and it required surgery to fix the problem. They kept saying I need an appointment to get the service.”* (Male, caregiver of a child physical impairment)

Caregivers who could not access specialised health services and rehabilitation often sought alternative therapies instead, such as herbal and natural remedies, or asked Sheiks to provide support. However, respondents said that no improvement was achieved after such support. In extreme instances, parents of children with behavioural conditions resorted to physical violence, hoping to control their child's behaviours through fear.

3.6 Utilisation of healthcare services

3.6.1 Services offered

Most of the children in the study were receiving no service at the time of the interview. Of those receiving, services offered and accessed varied. The most common was PT. Other services provided by the centres were educational services, speech therapy, behavioural/ skill modification, sensorimotor sessions, psychological support for parents and assistive technology. Not all services were available at all services and centres that respondents were registered.

Duration and frequency of the services available and received varied. Duration of the sessions varied from 15 min to 2.5 hours. Most reported a session frequency of 1, 2 or 3 days a week, although the occasional child received support on a monthly basis only. Most of the participants who received services were not satisfied with the frequency or duration of the services. Many wanted more support.

Further, there were very few reports about long-time engagement, because of limited appointments and availability. Some participants discontinued the services due to closure of the centre or fear this would happen.

Staff mentioned that the services in NGO-centres were overwhelmed, which contributed to long waiting times and limited sessions provided.

> *"Currently, I am providing the service to 35 children and there are another 40 children on the waiting list, which is awful since these children need immediate intervention. Not just our centre, each centre has a certain capacity and there are many people on the waiting list in each centre."* (Male, healthcare staff)

3.6.2 Cost of services

Cost was often reported as a barrier to access. Governmental rehabilitation services were free of charge, but participants could not use these rehabilitation services because of their refugee status. Private centres were too expensive, and some participants thought it was not worth the money. NGO-centres offered services for free, but as mentioned, these were scarce. Some participants thought the financial struggles would end if they had Turkish nationality. Out-of-pocket expenditures for weekly sessions and medicine were often reasons why participants could not afford continuous and long-term service. Services were more typically provided free in Antakya, although participants still faced high and prohibitive costs of travel.

3.6.3 Health-care workers

Some caregivers reported positive experiences with staff at specialised health and rehabilitation centres, referring to friendly and supportive care.

> *"Mothers tend to be in a bad mental condition in the early stages because they do not know anything about autism. The doctor tried to calm me down and told me that I should accept the fact that my son has autism and that I should support him to become better. They told me that they will provide me with whatever I need from now on and that they will be with me every step of the way."* (Female, caregiver of a child with autism)

However, some participants experienced discrimination from health staff and felt ignored, disrespected, and deceived, especially in Adana and Antakya. This was often related to their refugee status, rather than disability.

Many caregivers agreed that the staff were inexperienced in providing rehabilitation services and supporting children with disabilities. Some reported this as a cause for their child's limited improvement.

> *"They did not provide any special education or activities for my son; they were just babysitting. I wanted him to see other children and do activities with them. I thought it might make him better."* (Female, caregiver of a child with autism)

Staff training was a common topic mentioned by healthcare workers. Disability training was limited, impacting the quality and appropriateness of support from healthcare workers. Inexperience of staff was commonly mentioned. Specialised health staff interviewed suggested increased supervision of staff, training improvements, and hiring more experienced personnel.

3.7 Healthcare consequences

3.7.1 Child improvement

Almost all caregivers of children with disabilities who used rehabilitation services felt their children had improved functioning. In some cases, children improved slowly because of limited sessions, especially in the case of some intellectual and physical disabilities, but improvement was reported. This included improved speech, movement and behaviour. Parents accessing services also reported better awareness on disability and health conditions. Children interviewed were often enthusiastic to attend sessions.

In some instances, participants felt that their child did not improve because of language barriers between them and staff, resulting in inappropriate or sub-par care.

> *"In the last centre, the doctor was very good and she provided me with a set of exercises to do on my own at the house. However, when I started coming to Take My Hand centres, I realized that the language barrier had affected the way I do these exercises and that I performed them wrong for a long time."* (Female, caregiver of a child with autism)

Staff were often unable to speak Arabic and there were limited resources for Syrian refugees to learn Turkish. Translation services were also not available in many centres. Caregivers called for Arabic translators in specialised health and rehabilitation services.

3.7.2. Partnership between staff and patients

Collaboration and partnership between staff and caregivers were reported a common challenge. For instance, there were occasions when governmental hospitals did not provide information about a child's condition to their caregivers, resulting in misunderstanding and low confidence among caregivers.

Patient involvement in care was rarely discussed. Caregivers thought guidance, collaboration and communication with health staff was poor. Many wanted better collaboration with staff to continue care at home.

Summary of findings and recommendations

- Children with disabilities have complex health needs and parents experience mental health concerns. Interventions that support and sustain parents in their roles as long-term caregivers are warranted. Parent groups and peer-psychosocial support programmes, such as the WHO Caregiver Skills Training Programme or the UBUNTU interventions, offer structured training on caregiver skills and offer peer-support.
- Refugee status impacted healthcare access, as a result of limited awareness of entitlement and available services, limited availability of services, language difficulties, lack of available refugee rehabilitation centres and discrimination from the local population.
- Discrimination was a major theme discussed. Programmes such as the Friendship Project offer interventions designed to improve attitudes of children toward refugees.
- Health literacy and knowledge on disability among parents was low and efforts to improve this are needed. Such topics are covered in the parent groups previously described.
- There was a lack of information on available rehabilitation and specialised services. Improved outreach programmes would help, especially when utilising social media. Word of mouth was important and involving key leaders in the community in outreach programmes may be useful. It is important to remember that children with disabilities and caregivers are often isolated and hard to reach in the community.
- Language difficulties were a common barrier, leading to miscommunication between staff and patient, reducing satisfaction and healthcare quality. There is a need to expand interpreter services. QuickSpeak and Google Translate may offer a useful rapid solution, but need evaluation. Improving Turkish proficiency among refugee communities will also be beneficial.
- Getting a disability report is a challenge for many. Relief International should work with government and people with disabilities on how to improve this process.
- Transportation difficulties were common. Participants who received transport support, either through stipend or free provision, reported positively and there were calls for such schemes to be more widely rolled-out.
- Transportation costs, interpreter costs, medical costs and cost of private rehabilitation services all contributed to out-of-pocket expenditure, which were difficult for Syrian families, who often have limited work opportunities.
- The services offered resulted in improvements for children that could access them. However, services and appointments were too few to meet demand and rehabilitation programmes often lasted too short a time. Advocating for increased availability of services would help reduce unmet need.
- Few healthcare staff were included in this study and further research with this group would be useful to understand their perspectives and training needs.

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Appendices

Appendix A. Table of participants from the in-depth interviews

Variable	*Adana*	*Antakya*	*Istanbul*	*Total*
Sex of Caregiver				
Female	13	18	25	56 (74%)
Male	10	5	5	20 (26%)
Total	23	23	30	76 (100%)
Sex of Child with disabilities				
Female	7	9	8	24 (28%)
Male	22	17	24	63 (72%)
Total	29	26	32	87 (100%)
Age of Child				
0-6 years old	12	19	21	52 (60%)
7-11 years old	12	7	5	24 (28%)
12-18 years old	5	0	6	11 (13%)
Total	29	26	32	87 (100%)
Child disability				
Autism	10	7	14	31 (36%)
Musculoskeletal impairments	0	0	5	5 (6%)
Mental health condition	0	0	5	5 (6%)
Intellectual disability	1	2	2	5 (6%)
Physical impairment	0	7	4	11 (13%)
Congenital deformity	0	0	2	2 (2%)
Speech disorder	17	4	0	21 (24%)
Learning disability	1	1	0	2 (2%)
Hearing loss	0	2	0	2 (2%)
Not specified	0	3	0	3 (3%)
Total	29	26	32	87 (100%)

Appendix B. Table of key informants from the in-depth interviews

Variable	*Adana*	*Antakya*	*Istanbul*	*Total*
Sex of Key Informant				
Female	1	2	0	3 (33%)
Male	1	2	3	6 (67%)
Total	2	4	3	9 (100%)
Age of Key Informant				
18-29 years old	1	0	1	2 (22%)
30-39 years old	1	3	2	6 (67%)
40-49 years old	0	0	0	0 (0%)
>50 years	0	1	0	1 (11%)
Total	2	4	3	9 (100%)
Nationality				
Syrian	2	1	1	4 (44%)
Turkish	0	3	2	5 (56%)
Total	2	4	3	9 (100%)
Job title				
Project coordinator	0	0	1	1 (11%)
Project technical officer	1	0	0	1 (11%)
Technical manager	0	0	1	1 (11%)
Rehabilitation centre manager	0	1	0	1 (11%)
Speech therapist	0	1	1	2 (22%)
Physical therapist	0	1	0	1 (11%)
Blindness skills specialist	0	1	0	1 (11%)
Receptionist	1	0	0	1 (11%)
Total	2	4	3	9 (100%)
Organisation				
Take My Hand	0	0	2	2 (22%)
Mülteciler Derneği	0	0	1	1 (11%)
SENED Organization	2	0	0	2 (22%)
Fluka Alhurriye	0	4	0	4 (44%)
Total	2	4	3	9 (100%)

Appendix C. Table of participants from the focus group discussion

Variable	*Adana*	*Antakya*	*Istanbul*	*Total*
Sex of Caregiver				
Female	19	27	16	62 (87%)
Male	7	0	2	9 (13%)
Total	26	27	18	71 (100%)
Child disability				
Autism	16	0	6	22 (31%)
Musculoskeletal impairments	0	0	1	1 (1%)
Mental health condition	0	9	0	9 (13%)
Intellectual disability	2	0	2	4 (6%)
Physical impairment	0	2	6	8 (11%)
Visual impairment	0	2	0	2 (3%)
Speech disorder	8	12	2	22 (31%)
Hearing loss	0	2	0	2 (3%)
Epilepsy	0	0	1	1 (1%)
Total	26	27	18	71 (100%)